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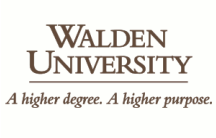

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Perspectives of Mental Health Counselors Providing Care to Adults with Intellectual Disabilities

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Walden University

College of Counselor Education & Supervision

This is to certify that the doctoral dissertation by

Cynthia Lea Minto

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

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Dr. Shelley Jackson, Committee Member, Counselor Education and Supervision Faculty
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Walden University
2018

Abstract

Perspectives of Mental Health Counselors Providing Care to Adults with Intellectual Disabilities

by

Cynthia Lea Minto

MA, Walden University, 2009

BS, Oberlin College, 1988

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Counseling Education and Supervision

Walden University

May 2018

Abstract

Adults with intellectual disability (ID) experience twice the rate of mental health disorders when compared to the general population. Despite increased prevalence of mental health disorders, caregivers supporting adults with ID rarely seek mental health counseling supports, but instead are referred to psychiatric services. There is limited understanding among researchers about the lack of counseling services for adults with ID. The purpose of this study was to explore the lived experiences of mental health counselors who have worked with adults with ID in a counseling relationship. Hermeneutic phenomenology was used to develop thick and rick experiential detail about counselor experiences providing services for adults with ID. The conceptual framework involved the social constructivist and hermeneutic phenomenological lenses. The 8 participants were recruited using a purposive snowball sampling method and provided data through semi-structured interviews. Data analysis involved coding for themes with the help of NVivo software. Findings indicated counselor perceptions of adults with ID as being stigmatized and marginalized within their communities, which aligned with literature. Adults with ID must be prepared for counseling and there must be appropriate adaptations to support meaningful participation and benefit from counseling interventions. Exposure to adults with ID was a factor in counselors being willing to engage with this population, and questions about counselor education and preparedness were a consistent theme. The social implications of exploring this gap will lead to a better understanding of counselor experiences and can inform the professional body about how to increase access to counseling services for adults with ID.

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Dedication

I dedicate this document to my loving husband, Paul Anthony Minto, and my mother, Louise A. Merriweather. Additionally, I dedicate this body of work to the many adults with intellectual disabilities who helped me gain a greater appreciation for their struggles, resilience, joys, hopes, and desires for a quality life.

Acknowledgments

There are many people who share in this accomplishment. My family is my rock. I know that I could not have accomplished this milestone without all your enduring encouragement when I felt stuck and overwhelmed and you told me to keep at it. I celebrate this with you.

Second, I extend sincere gratitude to the mental health counselors interviewed for this study. Without your willingness to share your experiences and insights, this study would not have been possible. Thank you for your commitment to supporting adults with ID and your contributions to helping them increase their quality of life.

Third, I have an awesome appreciation and gratitude for my committee members, Dr. Corinne Bridges and Dr. Shelley Jackson. Your guidance, encouragement, and insights through this process were ever-present. Your professionalism and coaching inspired me to completion. Thanks for believing in me.

Fourth, I want to acknowledge and express my appreciation for my colleagues and clients at Richmond Residential Services, Inc. I truly value your day-to-day passion and commitment to serve adults with ID and help them to lead a life well lived. It has been a privilege to work alongside you for 17 years, and thanks for your words of encouragement through this process. Additionally, I want to thank the individuals who have trusted me to support them in their lives. This is a trust that I have valued and has meant the world to me. Your candor, resilience, and enduring spirit inspired my passion to conduct this research.

Lastly, I must express the importance of my faith-filled walk with my Heavenly Father. Without your favor and enduring love, none of this would be possible. You are the reason for all things and words cannot express the gratitude in my heart.

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Chapter 1: Introduction to the Study

The American Association on Intellectual and Developmental Disability (AAIDD, 2017) defined intellectual disability (ID) as a cognitive disorder that impacts intellectual and adaptive functioning (conceptual, practical, social skills) that occurs prior to age 18. The prevalence of ID in the United States is approximately 15% (Boyle et al., 2011). For several decades, adults with ID have not been receiving quality mental health services, leading to assertions that adults with ID are underserved and overmedicated (Bhaumik, Ganghadaran, Hiremath & Russell, 2011; Corbett, 2011; Irvine & Beail, 2016; Mahan et al., 2010; Raffensperger, 2009; Reiss, Levitan & McNally, 1982; Tsiouris, Kim, Brown, Pettinger, & Cohen, 2012). Adults with ID rarely seek mental health services for themselves. Instead, caregivers of adults with ID refer them to psychiatric services for three main reasons: self-injurious behavior, property destruction, and aggression (Bouras & Holt, 2010; Deb, Unwin, & Deb, 2015; Feldman, Atkinson, Foti-Gervais, & Condillac, 2004; Jahoda, 2016; Oliver, Miller & Skillman, 2005; Raffensperger, 2009; Ulzen & Powers, 2009). Frequently, adults with ID are excluded from traditional mental health counseling services because it has been assumed that they will not benefit from this type of intervention (Corbett, 2011; Irvine & Beail, 2016; Jahoda, 2016; Mason & Scior, 2004; Raffensperger, 2009; Taylor & Knapp, 2010). The phenomenon relates to the concept of diagnostic overshadowing (DO). DO is defined as the failure to diagnose adults with ID with a mental health disorder and linking, instead, any observed symptoms of mental health distress to their ID (Irvine & Beail, 2016;

Jahoda, 2016; Jopp & Keys, 2001; Mason & Scior, 2004; Reiss, Levitan & Szyszko, 1982; Taylor & Knapp, 2010).

Concern about accurate diagnostic assessment for adults with ID has been noted in the literature (Bhaumik et al., 2011; Charlot & Beasley, 2013; Corbett, 2011; Hurley, 2006; Irvine & Beail, 2016; Raffensperger, 2009; Taylor & Knapp, 2010). Morasky (2007) and Irvine and Beail (2016) noted that many adults with ID have limitations in verbal expression and poor memory, which impact their ability to offer quality subjective information to clinicians who are attempting to assess for the presence of mental health disorders. Finlay and Lyons (2002) offered research about acquiescence bias. Acquiescence bias is defined as the tendency to answer in the affirmative to please the interviewer (Finlay & Lyons, 2002). While acquiescence bias does occur in interviews conducted with adults with ID, Finlay and Lyons asserted that the prevalence of this phenomenon cannot always be explained by a desire to please but, also, the complexity of the questions being asked during the interview may also be an issue. These factors complicate the ability to obtain an accurate diagnosis when working with adults with ID, which in turn may complicate treatment decisions (Bouras & Holt, 2010; Fletcher, Stavrakaki, Loeschen, & First, 2007; Irvine & Beail, 2016; Jahoda, 2016). Despite these limitations in obtaining an accurate diagnostic assessment, there is literature about the effectiveness of cognitive-behavioral, psychodynamic, and applied-behavioral therapeutic interventions when offered to adults with ID (Barrowcliff, 2008; Beail & Jackson, 2013; Bhaumik et al., 2011; Corbett, 2011; Davis, 2011; Nicholl & Beail, 2013).

Few researchers have sought to understand the minimal counseling services offered to adults with ID; this is surprising considering the extent to which this population utilizes outpatient psychiatric services and acute inpatient hospitalization. Further, there is limited understanding of the experiences of mental health counselors working with adults with ID. Increased understanding of the perspectives of mental health counselors who have counseled adults with ID will raise awareness in the counseling profession and improve access to counseling services, as well as enhance counselor competency. Moreover, this study was an attempt to understand the essence of the experience of mental health counselors working with adults with ID, to provide a baseline understanding of how counselors perceive this group, and to illuminate possible counselor competency deficits that, when addressed, could potentially result in increased access to counseling resources. Increasing access to quality mental health care would significantly improve quality of life and help adults with ID live more fulfilling lives within their communities (Corbett, 2011; Dykens, 2006; Koch et al., 2015; Marini, Glover-Graf, & Millington, 2012; Russell, Hahn & Hayward, 2011). The goal of this research, also, is to enhance the ability of counselor educators to train and support emerging mental health counselors to meet the needs of this population.

Through this phenomenological research, the goal was to increase understanding of how counselors work with adults with ID, and an increased understanding of these experiences helps illuminate the barriers contributing to the lack of counseling services offered to this vulnerable population. Additionally, this research provided additional understanding of the current needs of adults with ID as defined by counselors who

currently work with ID clients. By increasing mental health professionals' understanding of the lived experiences of counselors engaged in a counseling relationship with adults with ID, I have sought to identify information that can be shared with counselor educators and the wider professional community about the specific needs of adults with ID as they engage in a counseling relationship. Furthermore, this work may well identify counselor competency strategies needed when working with this client demographic. As information about these lived experiences emerges, the increased understanding may, I hope, result in increased awareness of strategies that will inform the professional body and serve to raise awareness and move to increase access to mental health counseling services for adults with ID. In this chapter, I have explored the background of the problem, cited the research gap, established the problem statement, conceptual framework, assumptions, scope, limitations and delimitations, and significance, and, finally, provided a summary.

Background

In 1936, Chidester and Menninger stated, "Mental retardation has long been looked upon as an organic condition therapeutically hopeless" (p. 616). In 1982, Reiss, Levitan, and McNally stated, "Mentally retarded people may constitute one of the most underserved populations in the United States" (p. 361). Historically, treatment of people with mental illness and ID has been in the form of institutional care (Bouras & Holt, 2010; Larson, Lakin, & Hill, 2012; Lemay, 2009). Advocates have argued that inclusion is a concept of exposure to the wider community, and normalization is advocacy aimed at people with ID to help them receive the same exposure to and experiences of the

community that are afforded to all other citizens (Bouras & Holt, 2010; Kim, Larson, & Lakin, 2001; Landesman & Butterfield, 1987; Larson et al., 2012; Lemay, 2009; Taylor, 2001). Advocacy efforts led the way for legislation aimed at ensuring that adults with ID received opportunities for services in the least restrictive environment (LRE). A swell of litigation and legislation, fueled by the arguments that adults with ID should receive care in their communities and should not be segregated in institutions, resulted from the increased advocacy for adults with ID to be included in the community (Bouras & Holt, 2010; Larson et al., 2012, Lemay, 2009). The proponents of the LRE principle based their arguments on the constitutional principles of due process, equal protection, and liberty (Lemay, 2009; Taylor, 2001). The Americans with Disabilities Act (ADA) of 1990 was a direct result of advocacy. The ADA and the Olmstead Act in 1999 laid the groundwork for the deinstitutionalization movement in America (Kim et al., 2001; Lemay, 2009; National Council on Developmental Disabilities [NCD], 2016; Routh, 2006; Taylor, 2001).

Beadle-Brown, Mansell and Kozma (2007), Lemay (2009), and Larson et al. (2012) discussed the impact of deinstitutionalization on adults with ID and found that, consistent with previous research, adults with ID experienced improvements in their quality of life, improved their adaptive behavior, and gained more choice. However, these gains did not always translate into expanded social networks and community inclusion (Dykens, 2006; Kim et al., 2001; King-Andrews & Farrell, 2006; Koch 2015; Lemay, 2009). As the concepts of LRE spurred more deinstitutionalization, adults with ID, after having lived in large paternal institutions, experienced problems of assimilation within

their communities (Hartley & MacLean, 2009; Hastings, Hatton, Taylor & Maddison, 2004; Lemay, 2009; NCD, 2016, Taylor, 2001). Exposure to the wider community resulted in increased problems with transition into that community, as well as exposure to alcohol and drug abuse, crime, sexual assault, and poverty (Corbett 2011; Dykens, 2006; Hastings et al., 2004; NCD, 2016; Raffensperger, 2009; Taylor & Knapp, 2013; Tomasulo & Razza, 2006).

It is important to explore the background of literature and, by doing so, consider how adults with ID are viewed as recipients of mental health services. Corbett (2011) discussed the social exclusion and neglect of adults with ID from counseling professionals, despite a higher rate of prevalence of mental health disorders, increased vulnerability, and social exclusion. Raffensperger (2009) offered evidence that adults with ID benefit from counseling interventions. However, there is a lack of mental health counselors actually working with this population (Costello, Hardy, Tsakanikos & McCarthy, 2010; Drucker, 2011).

Bradley and Cheetham (2010), Crossley and Withers (2008), Russell et al. (2011), and Mahan et al. (2010) concurred that adults with ID experience a higher prevalence of mental health disorders when compared to the general population and are more vulnerable. There has been evidence that adults with ID are heavily medicated with psychotropic medications for challenging behaviors and in lieu of a proper mental health diagnosis (Deb et al., 2009, Deb et al., 2015; Deb & Unwin, 2007; Mahan et al., 2010). Psychotropic—specifically antipsychotic—medications can have significant side effects, and if not carefully monitored can have dramatic poly-pharmacological and metabolic

results that may significantly decrease quality of life (Crossley & Withers, 2009; Hemmings, Gravestock, Pickard & Bouras, 2006; Holden & Gitlesen, 2003, 2004; Mahan et al., 2010; Posey, Stigler, Erickson, & McDougle, 2008).

Krahn, Fox, Campbell, Ramon and Jesien (2010) and Weiss, Lunsky, Gracey, Canrinus, and Morris (2009) cited high utilization of acute psychiatric hospitalization and outpatient psychiatry services as the first-line approach to treating mental health and behavioral concerns (aggression, property destruction, and self-injurious behavior) presented by adults with ID. The authors cited that inpatient care and psychiatry services are expensive and suggested coordinated mental health services, such as counseling, are less restrictive, preventative in nature, and more cost-effective as interventions for adults with ID but are not widely available (Corbett, 2011; Costello et al., 2010; Lunsky, Gracey, Bradley, Koegl, & Durbin, 2011; Weiss et al., 2009).

Literature suggested that cognitive behavioral therapy (CBT) is an effective intervention for adults with ID. Wright (2013) asserted that CBT interventions demonstrated effectiveness to address anxiety in adults with ID. Nicoll, Beail, and Saxon (2012) asserted that CBT interventions are effective in working with anger and curbing aggressive behaviors in adults with ID. Ghafoori, Ratanasiripong, and Holladay (2010) explored the utility of group/individual counseling using CBT interventions. Khan and Beail (2013) and Pert et al. (2013) conducted qualitative research attempting to understand the perceptions of adults with ID receiving CBT counseling interventions. The authors noted that CBT interventions are effective with this population and that

adults with ID receive benefit from unconditional positive regard and therapeutic alliance.

Adults with ID are vulnerable individuals in their communities and literature suggested they are twice as likely to experience mental health disorders, leading them to become heavy users of emergency and crisis mental health services (American Psychiatric Association [APA], 2000, 2013; Irvine & Beail, 2016; Krahn et al., 2010; Weiss et al., 2009). Despite this, adults with ID are the least likely to receive mental health counseling services when compared to nondisabled people and instead are treated by psychiatrists for behavioral issues like self-injury, property destruction, and aggression (Corbett, 2011; Deb et al., 2015;Unwin & Deb, 2009; Jahoda, 2016; Oliver et al., 2005). Adults with ID experiencing mental health or behavioral problems receive treatment for their emotional and behavioral problems by psychiatrists as the first line of support. To understand why there seems to be such a lack of mental health counseling services offered to adults with ID, it is necessary to understand the perceptions of mental health counselors who have treated adults with ID in a counseling relationship. When exploring this issue in the literature, I found no study that offered insight into how mental health counselors perceive adults with ID. Consequently, there is a gap in the literature about how mental health counselors perceive adults with ID. This study was meant to explore the lived experiences of mental health counselors who work with adults with ID in a counseling relationship. I hope that this study helps illuminate needed information, with the goal of raising awareness as to the unique needs of adults with ID and how best, also, to serve their needs in regard to a counseling relationship.

In this first chapter, I introduce components of the study. My interest is in exploring the lived experiences of mental health counselors providing counseling services to adults with ID. The problem statement, derived from gaps in the literature, and the purpose and the nature of the inquiry, further outlines the research study. Additionally, this research is a qualitative hermeneutic inquiry using a constructivist lens to examine the phenomenon. Finally, I discuss assumptions, limitations, scope, delimitations, and the significance of the study.

Problem Statement

Adults with ID have twice the rate of co-occurring disorders as compared to the general population (APA, 2000, 2013; Bradley & Cheetham, 2010; Corbett, 2011; Irvine & Beail, 2016), are treated heavily with psychotropic medications (Bradley & Cheetham, 2010; Crossley & Withers, 2009; Irvine & Beail, 2016; Mahan et al., 2010; Russell et al., 2011), and experience high rates of acute psychiatric hospitalization (Krahn et al., 2010; Raffensperger, 2009; Weiss et al., 2009). This population is an invisible and particularly vulnerable group within their communities (Corbett, 2011; Hartley & MacLean, 2009; Irvine & Beail, 2016; Taylor & Knapp, 2013). These vulnerabilities result from the lack of support systems, multiple life events secondary to lack of autonomy, and a high frequency of abuse and neglect (Beadle-Brown, Mansell, Cambridge, Milne, & Whelton, 2010; Corbett, 2011; Hartley & MacLean, 2009; Irvine & Beail, 2016; Lunsky et al., 2011). Adults with ID frequently do not self-refer for care and caregivers do not refer for life issues, but instead are referred for such issues as property destruction, aggression, and self-injurious behavior to psychiatric services as the first and singular approach to

treatment (Corbett, 2011; Crossley & Withers, 2009; Feldman et al., 2004; Hartley & MacLean, 2009; Irvine & Beail, 2016; Oliver et al., 2005; Raffensperger, 2009; Taylor & Knapp, 2013). Traditionally, adults with ID were excluded from mental health counseling services, because it was assumed that they will not benefit from counseling interventions (Bouras & Holt, 2010; Corbett, 2011; Irvine & Beail, 2016; Raffensperger, 2009).

This exclusion from service is related to the concept of DO (Bouras & Holt, 2010; Irvine & Beail, 2016; Jahoda, 2016; Jopp & Keys, 2001; Reiss, Levitan & Szyszko, 1982). DO is defined as the failure to diagnose adults with ID with a mental health disorder while linking symptoms of mental health distress to their ID (Irvine & Beail, 2016; Reiss, Levitan & Szyszko, 1982). Research suggested that adults with ID can participate and benefit from the use of CBT interventions. Research demonstrated that CBT interventions effectively address a variety of presenting mental health problems such as anger, bereavement, psychosis, and anxiety (Barrowcliff, 2008; Brown & Marshall, 2006; Ghafoori et al., 2010; Hans & Hiller, 2013; Hassiotis et al, 2011; Irvine & Beail, 2016; Jahoda, Dagnan, Kroese, Pert, & Trower, 2009; Kauffman, 2011; Morasky, 2007; Nicoll et al., 2012; Taylor & Knapp, 2013). The lack of counseling options for adults with ID presents a problem, because it does not comply with the multicultural ethical mandate supported by the American Counseling Association (ACA) and Council for Accreditation for Counseling and Related Educational Programs (CACREP) standards. These standards outline the edict, which supports the necessity to offer competent counseling services that appeal to diverse groups (ACA, 2014; CACREP, 2009).

Purpose of the Study

The purpose of this qualitative hermeneutic phenomenological research was to understand the lived experiences of counselors working with adults with ID. I sought to increase understanding of how counselors work with adults with ID, and increased understanding of these experiences has helped reveal the barriers contributing to the lack of counseling services offered to this vulnerable population. Additionally, this research increases understanding regarding the current needs of adults with ID as defined by counselors who currently work with ID clients. With an increased understanding of the lived experiences of counselors engaged in a counseling relationship with adults with ID, this study has identified information that can be shared with counselor educators and the wider professional community concerning the specific needs of adults with ID as they engage in a counseling relationship. Furthermore, this work has identified counselor competency strategies needed when working with this client demographic. As information about these experiences comes to light, the increased understanding of the lived experiences may also result in increased awareness of strategies, which informs the professional body and may serve to raise awareness and move to increase access to mental health counseling services for adults with ID. Moustakas (1994) asserted that phenomenology highlights an idea and hermeneutic phenomenology is an effort that seeks to interpret specific phenomena through the lens of human experience.

Research Question

What are the lived experiences of mental health counselors who have engaged in counseling relationships with adults with ID?

Theoretical/Conceptual Framework for the Study

Qualitative inquiry offers the researcher an understanding of human experiences in a manner that is not achievable through quantitative methods (Moustakas, 1994; Patton, 2015; Seidman, 2013). Qualitative designs allow a rich and whole experience about a phenomenon to be obtained from the participants, which is not focused on parts, explanations, or measurements (Moustakas, 1994). This study is qualitative and remains within the phenomenological realm of inquiry. The goal of phenomenology is to understand and describe the meaning of participant lived experiences. Phenomenology is constructivist and seeks to provide rich descriptions of participant experiences (Creswell, 2014; Moustakas, 1994; Patton, 2015). Hermeneutic phenomenological approaches to data collection and interviewing offer an understanding of multiple frames of reference and realities, which can and do exist from participant to participant (Hays & Wood, 2011; Moustakas, 1994; Seidman, 2013). These realities are contextually relevant and important in understanding the participants' collective and internal perspectives related to the research questions (Moustakas, 1994; Seidman, 2013).

Nature of the Study

Virginia is experiencing a systemic change related to the closure of institutions and the subsequent offering of services and supports in the LRE manner. With this challenge and system transition, the community is the primary focus of support for adults with ID. Chapter 2 outlines a review of literature that describes problems with lack of mental health counseling and an overreliance on outpatient psychiatry and psychotropic medications as the main treatment options for adults with ID. This is concerning because

literature has suggested that CBT, psychodynamic, and mindfulness psychotherapy has been deemed effective with adults with ID. (Beail & Jackson, 2013; Irvine & Beail, 2016; Raffensperger, 2009). Given this information, there are still too few mental health counselors providing care to adults with ID in a counseling relationship.

My recruitment efforts focused on e-mail solicitation from the Virginia State ACA, local community service boards, and Facebook user groups to recruit mental health counselors who have had actual experience in a counseling relationship with adults with ID. The invitation provided explanation of the problem statement and the purpose of the study (Appendix C). From the responses gathered, I selected a purposeful sample of eight counselors, with a target goal of six to 10, to participate in one individual semistructured interview each. The focus of the study's participant recruitment was Virginia. However, I widened the geographic area to span the mid-Atlantic area to increase the likelihood of gaining participants. Whenever possible, in-person interviews were performed, but the use of technology (Skype video conferencing) to increase participation and limit expenses associated with the study has also been utilized.

According to Seidman (2013), the purpose of the interview in hermeneutic phenomenology is to understand participant meaning derived from their experiences. Given the research questions offered for this study, interviewing was the most natural direct methodology to achieve a contextual understanding of the research questions related to the lived experiences and the meaning of participant experiences, beliefs, perceptions, and thoughts about providing counseling services to adults with ID (Seidman, 2013). I conducted a single 90-minute interview with each participant that

focused on the participant's history and experience counseling adults with ID, as well as the context and meaning-making of their experiences of counseling adults with ID. To maximize time and ensure that information was rich and abundant, I provided an open-ended questionnaire to each participant prior to the start of the interview. The questionnaire captured information such as demographics and experience, as well as information about training, interventions used, and outcomes related to counseling experiences with adults with ID (Appendix A). The interviews were audio-recoded, transcribed, and member-checked for accuracy. I coded the information and used NVivo software to aid in the analysis of themes (Maxwell, 2013; Seidman, 2013). I recruited participants for the study using an e-mail solicitation. The Virginia Board of Counseling Listserv, Virginia State ACA, local community service boards, and Facebook user groups were the vehicles used to invite mental health counselors who have counseling experience with adults with ID to participate in the study.

This recruitment process allowed the following inclusion criteria to be met: licensed professional counselors in good standing with the Virginia Board of Counseling who have self-identified as having actual counseling experience with adults with ID who have a minimum of 2 years' experience. Inclusion criteria were limited to a minimum of 2 years of counseling experience to ensure that there were as many participants as possible for the study. I also expanded my geographical search to the mid-Atlantic area, with the inclusion criteria adjusted to reflect that the counselor was to be licensed in good standing within their state. These actions were based upon research that suggested there are not many counseling professionals currently providing counseling services to adults

with ID (Corbett, 2011; Irvine & Beail, 2016; Prout & Browning, 2011). My hope was that by lowering the inclusion criteria to 2 years' experience, it would serve to offer maximum latitude for counselor participation. The invitation explained the problem statement and outlined the purpose of the study. From the responses gathered, I determined a purposeful sample of counselors meeting the inclusion criteria based upon the number positive responses to the initial invitation e-mail. Eight participants were selected for individual 90-minute semistructured interviews. The interview questions were open-ended and semistructured to align with the focus of the research questions. The interviews were audio-recorded, transcribed, and member-checked for accuracy. Other sources of data include field notes and a personal journal. From the data, I bracketed information to reduce bias and identify emerging themes from the interviews (Maxwell, 2013; Seidman, 2013).

Definitions

Counseling relationship: A relationship that is based upon trust, mutual respect, and alliance as a part of a defined process where a counselor is working with a client to help them clarify, define, or resolve their problem. This can be based upon an emotional problem or an issue that has the client "stuck," or hindered, and feeling that they need support to resolve their emotional issues and move toward wellness and resolution of symptoms (Sexton & Whiston, 1994).

Developmental disability: The National Council on Disabilities (2016) described developmental disability as a chronic condition that may manifest as cognitive, physical, or a combination of both. Developmental disabilities affect people for the duration of

their lives, causing significant impairment in everyday life with respect to self-care, communication, learning, and mobility. The term *developmental disability* has been used interchangeably with many other terms like *mental retardation*, *intellectual disability*, and *learning disability*.

Diagnostic overshadowing (DO): This term was created by Reiss, Levitan, and Szyszko (1982) and refers to the phenomenon in which clients with an intellectual disability do not receive a mental health diagnosis because it is assumed that their symptoms are a product of their intellectual disability. Due to the language deficits present in many clients with an intellectual disability, clients are not given a mental health diagnosis, even though a person with normal intelligence presenting similar problems would be diagnosed.

Inclusion: This term is used to demonstrate the concept of opening and expanding community services to persons with mental retardation and other disabilities so that they may enjoy the same resources (Kim et al., 2001; Taylor, 2001).

Intellectual disability (ID): The AAIDD (2017) described ID as a limitation in intellectual and adaptive behavior expressed through conceptual, social, and practical adaptive skills. The disability originates from before age 18 (AAIDD, 2017; Schalock et al., 2007). The APA (2013) defined ID in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*) as a long-term cognitive disorder encompassing deficits in adaptive functioning in the domain areas of language (reading, writing, reasoning, knowledge, and memory), social (empathy, social judgment, interpersonal communication skills), and practical skills, which involve self-management and self-care

skills (personal care, job responsibilities, money management, community safety, and school/occupational functioning, etc.; APA, 2013).

Least restrictive environment (LRE): This term is primarily a legal term that was used to earmark how and where support services should be offered. Specifically, Turnbull (as cited in Taylor, 2001) defined the LRE as a place or setting that offers the minimal amount of structure necessary to provide effective services to people with mental retardation (Taylor, 2001).

Mental retardation: According to the *Diagnostic Statistical Manual of Mental Disorder*s (4th ed., text rev.; *DSM-IV-TR*; APA, 2000), mental retardation is described as an IQ score of approximately 70 or below along with deficits in the following areas: communication, self-care, home living, social and interpersonal skills, use of community resources, as well as a lack of functional skills in academics, work, leisure, health, and safety (APA, 2000). The deficits must be present before 18 years of age. There are four levels of severity of mental retardation: mild, moderate, severe, and profound.

Normalization: This term was coined in the field of human services and rests on the premise that quality of life increases as access to culturally typical activities and settings increases (Landesman & Butterfield, 1987).

Assumptions

For this study I assumed that there were counselors providing counseling supports to adults with ID willing to partner with me in this research. It was, and is, assumed that counselors working with adults with ID in a counseling relationship have contributions to make that are helpful and meaningful to the profession as a whole. I also assumed that the

counselors interviewed were honest and truthful in relating their experiences, offering veracity to the information gathered. This is important because previous literature has indicated that adults with ID are a neglected clinical population that have significant mental health needs that remain generally unaddressed through counseling options, with these needs instead more often supported by acute inpatient psychiatric services and/or outpatient psychiatry services (Bouras & Holt, 2010; Corbett, 2011; Irvine & Beail, 2016; Taylor & Knapp, 2013). It is necessary to explore the experiences of mental health counselors who have actually provided support to understand what counselors believe are the unaddressed needs of adults with ID. This information is needed to inform the professional body of counselors and counselor educators.

Scope

The scope of the research was limited to mental health counselors providing counseling services to adults with ID within the community. The rationale for choosing this lens is that it aligned with the research question, and inquiry helped to illuminate current lived experiences of adults with ID engaged in counseling. The social constructivist theoretical lens framed the knowledge gained to investigate the lived experiences of mental health counselors. The lived experiences of mental health counselors aided in developing an understanding of how mental health counselors view working with adults with ID. Social constructivist theory helped to develop conclusions about the meaning and add to the body of knowledge about this important topic. Schwandt (2000) described the social constructivist lens as the ability to develop concepts, models, and schemas about the world, which helps to determine the meaning of

experiences. Exposure to new information is modified on the backdrop of shared information and understanding about the environment. It is important to note that meanings are not always an individual process; instead, meanings are derived through social interaction (Creswell, 2014; Moustakas, 1994). I have used the constructivist lens as a guide to explore the lived experiences of mental health counselors who have actual counseling experience with adults with ID. It has been of importance to understand how mental health counselors view adults with ID and what they have come to know about this population through their interactions. The interpretive framework used in this qualitative design will help inform the field—specifically counselor educators—to meet the needs of this underserved client population. This theoretical lens was the best fit because it allowed the focus of the research to align with the research question.

Additionally, the hermeneutic phenomenological strategy in this research was useful when combined with a social constructivist lens. According to van Manen (1997), hermeneutic phenomenology is the vehicle that propels scientific inquiry into the lived experience. A more detailed discussion of hermeneutic phenomenology occurs in Chapter 2 and Chapter 3.

Delimitations

The delimitations of this study are the boundaries of the research participants. Specifically, I only interviewed licensed mental health counselors with a minimum of 2 years' licensed experience and direct counseling experience with adults with ID. Other factors included the limited geographic area of recruitment and the limitation of inclusion of mental health counselors who have worked in a counseling relationship with adults

with ID. These parameters allowed for the central research goal of the study, which was a greater understanding of the lived experiences of mental health counselors who have provided counseling to adults with ID.

Limitations

The limitations of this study include the inability to generalize to a broader population due to the small sample size and the subjective nature of phenomenology as a methodology (Creswell, 2014). Although the design of this study may be replicated, the conclusions of this study will not be transferable to other populations or areas due to the design and other confounding variables that may not be able to be controlled for.

Another limitation remains the potential for researcher bias. Patton (2015) indicated a critique of qualitative research is that bias can be a factor as the researcher is collecting and interpreting the data. Patton posited that it is impossible to be completely neutral in research, qualitative or quantitative. However, several measures designed to reduce subjectivity are needed to reduce bias and increase result trustworthiness. Specifically, systematic data collection, field journals, and member-checking are methods used to increase the trustworthiness of qualitative research techniques (Patton, 2015). In this research, I used systematic data collection, field notes, and member-checking to assist with the trustworthiness of the research.

Significance

Adults with ID are at increased risk of co-occurring mental health disability (Bouras & Holt, 2010; Corbett, 2011; Irvine & Beail, 2016; Raffensperger, 2009; Taylor & Knapp, 2013) but are the least likely to receive mental health counseling as a treatment

intervention as compared to the general population (Corbett, 2011; Irvine & Beail, 2016; Taylor & Knapp, 2013). Research is needed to understand the experiences of mental health counselors serving this group. Increased understanding will help to clarify what competencies are required, which will benefit counselors and counselor educators. Greater understanding could lead to an increase in advocacy and help ensure that the particular needs of adults with ID are met. Increased knowledge about the lived experiences of mental health counselors providing services to adults with ID will support the moral and ethical mandates of multicultural competency as outlined in the ACA (2014) Code of Ethics and the CACREP (2009) Standards.

Ethical conduct is a primary consideration for professionals and researchers. Ethical research is a necessary consideration for professional identity and to protect the rights of participants involved (Creswell, 2014). The research participants for this study were mental health counselors in Virginia. The risk to this group was minimal. Appropriate informed consent was offered so that participants could fully evaluate the benefits and risks associated with this study. Confidentiality was maintained by storing records and data in a locked cabinet, and computers were secured via password protection (Creswell, 2014).

Summary

This chapter offered an introduction to the study and identified the social problem of the current lack of available mental health counseling services offered to adults with ID. Additionally, the chapter outlined the background, problem statement, purpose of the study, research questions, nature of the study, theoretical framework of the study, scope

and delimitations, and limitations, as well as the significance of the research. Chapter 2 offers a review of the relevant literature, focusing on several key areas that help offer depth and perspective about current knowledge of adults with ID and their mental health care and supports.

Chapter 2: Literature Review

Introduction

This phenomenological hermeneutic research was an exploration of the lived experiences of mental health counselors who have provided mental health counseling to adults with ID. In order to fully understand the context of care, it is necessary to explore the definition of ID and associated terms related to this study, the history of services for adults with ID, deinstitutionalization, the literature surrounding DO, and assessment of mental health disorders in adults with ID. Lastly, it is important to understand the literature outlining the mental health interventions used to support adults with ID in the community.

Adults with ID are a vulnerable population and experience twice the prevalence of co-occurring mental health disorders when compared to the general population (APA, 2000, 2013; Brown, Brown & Dibiasio, 2013; Corbett, 2011; Irvine & Beail, 2016; Matson & Shoemaker, 2011; Taylor & Knapp, 2013). Adults with ID are routinely referred for psychiatric treatment due to challenging or problem behavior (Bouras & Holt, 2010; Brown et al., 2013; Deb et al., 2009; Deb et al., 2015; Donley, Chan, & Webber, 2012; Feldman et al., 2004; Oliver et al., 2005; Raffensperger, 2009). Problematic or challenging behavior is defined as socially unacceptable behavior that causes distress, harm, or disadvantage to themselves or others, damage to property, and usually needs some intervention for safety (Deb et al. 2015). The course of treatment for adults with ID is addressed in the form of crisis referrals to acute inpatient psychiatry followed by referral to outpatient psychiatry (Bouras & Holt, 2010; Crossley & Withers,

2009; Deb et al, 2009, 2015; Weiss et al., 2009). Outpatient psychiatric interventions seek to address the problems or challenging behaviors with psychotropic medications (Crossley & Withers, 2009; Deb et al., 2015; Gentile, Gillig, Stinson, & Jensen, 2014; Krahn et al., 2010; Rose, O'Brien, & Rose, 2007; Ulzen & Powers, 2008; Weiss et al., 2009). According to recent literature, adults with ID benefit from the use of mental health therapeutic interventions (Hemm, Dagnan, & Meyer, 2015; Irvine & Beail, 2016; Jahoda, 2016; Unwin, Tsimopoulou, Kroese & Azmi, 2016). Specifically, CBT can address a variety of mental health problems such as anger (Dodd et al., 2013; Nicoll et al., 2013; Pert et al., 2013; Rose, Dodd, & Rose, 2008), grief (Clute, 2010), psychosis (Barrowcliff, 2008), and anxiety and depression (Hassiotis et al., 2011; Morin, Cobigo, Rivard, & Lepine, 2010; Wright, 2013). This chapter focuses on reviewing the pertinent literature about mental health needs and how services offered are tailored to meet the specific needs of adults with ID. The gap in the literature is revealed in the lack of understanding of the perspectives and lived experiences of mental health counselors who have provided counseling supports to adults with ID in the community. The purpose of this study is to add to the body of knowledge concerning how best to serve adults with ID within a counseling relationship. This inquiry offers, as its goal, insight into the unique needs of adults with ID and information for mental health counselors information that could expand their knowledge about adults with ID. Increased information may result in an increase and expansion of mental health resources available to adults with ID in their communities and thereby improve quality of life.

Literature Search Strategy

The search criteria for this topic is based on a search of EBSCO databases, PsyINFO, PsyARTICLES, MEDLINE, Academic Search Premier, CINAHAL Plus Text, SOCINDEX, ERIC, and the Walden Dissertation database within the Walden University Library. Given past research efforts in the field of mental retardation and developmental disabilities, many of the articles date from the 1980s to present day. The following keywords were used to navigate the search: *mental illness, psychopathology, cognitive therapy, psychodynamic, mindfulness therapy, mental health treatment of adults with ID, counseling, developmental disabilities, diagnostic overshadowing, intellectual disabilities, mental retardation, quality of life, psychotropic medication, mental health counselors and adults with ID, assessment of mental health disability, counselor perspectives, hermeneutic phenomenology, phenomenological interviewing, social constructivism,* and *deinstitutionalization*. Additionally, I conducted a physical search of the following: *Journal of Mental Retardation, American Journal of Mental Deficiency, Journal of Applied Behavioral Analysis, The NADD Bulletin*, and the Internet.

Social Constructivist Theory

I grounded this research in the social constructivist theory. Constructivist theory has historical foundations going back to the ancient Greek philosophers (Moss, 1992). Specifically, the Greek philosopher Epictetus asserted that people are not distressed by *things*, necessarily, but rather by the views or meanings that they attach to them (Moss, 1992). George Kelly influenced the development of social constructivist perspective within the field of psychology (Seligman, 2006). Kelly wrote *The Psychology of*

Constructs in 1955 and asserted that people view their world through a series of symbols that represent their beliefs or thoughts of themselves and their social environments (Kelly, 1955). Mahoney (1988) asserted that people have very individual emotional and psychological realities. According to Mahoney, there are five basic themes of constructivism. First, people are active participants of their realities and a person's choices, actions, and beliefs will influence their experiences. Second, people need and will develop order and organization to their world and experiences. Third, people need to develop a distinct sense of self-identity to determine the connection to the environment. Fourth, people must derive meaning from external social processes and symbols, and lastly, people need to operate within their environment and derive meaning from the social processes in which they participate (Mahoney, 1988).

The goal of social constructivist theory is to view a particular social issue through the lens of the people who are experiencing the problem (Niemeyer,1993). Schwandt (2000) operationalized the social constructivist lens about phenomenological inquiry. Social constructivist theory assumes that the mind is working to derive an understanding of one's environment. People acquire knowledge and derive meaning about what happens in the world (Schwandt, 2000). Schwandt stated, "Knowledge is not passive—a simple imprint on the mind—but active; that is, the mind does something with these impressions, at the very least forming abstractions or concepts" (p. 197). In other words, people make meaning or develop "constructs" about their experience. The meaning-making is grounded in historical and sociocultural meanings that are tested and retested against a palate of shared understandings, language, and customs (Schwandt, 2000). I used social

constructivist theory to understand how mental health counselors who have worked with adults with ID, in their work as mental health counselors, view such people. Through this lens, more information about counselor lived experiences could inform the wider profession about the needs of adults with ID in a counseling relationship.

Transcendental and Hermeneutic Phenomenology

Phenomenology is a branch of philosophy and also an approach that qualitative researchers use to help illuminate how people view their world and how they identify the meaning of phenomena as such things occur in the world (Maxwell, 2013; Sloan & Bowe, 2014; van Manen, 1997). As it relates to getting to the essence of understanding the experiences of people as they experience phenomena, qualitative research methodologies strive to help portray how people experience their environments and are based upon the premise that the world is socially constructed and very complex (van Manen, 1997). There are two main branches of phenomenology: transcendental and hermeneutic.

Husserl (1965) identified that phenomenology is a historical philosophical process that seeks to understand the truth people experience through an investigative process. This investigative process seeks to explain the essence of phenomena through a process of reflecting on experiences. Husserl's view of phenomenology is transcendental in that it seeks to understand knowledge through analysis and description (Husserl, 1965). Husserl posited that the transcendental approach must compel the researcher to set aside their previous views, judgments, and experience; if not, this will be a barrier to understanding the phenomena as studied. Husserl offered the concept of intentional focus on the

phenomena studied. This allows the researcher to become open to understanding an experience. Moustakas (1994) defined this process in qualitative phenomenology as bracketing, a process that allows for the researcher to set aside their biases about the phenomena being studied. According to Husserl, the intentional focus of transcendental phenomenology allows the researcher to engage in reduction of experiences to get at the essence of the experience not translated through a cultural lens.

In contrast to Husserl (1965), Heidegger's view of phenomenology differs from Husserl's in three distinct ways: time, the interpretive framework, and the importance of setting aside preconceived perspectives of the researcher in the process of inquiry (Maxwell, 2013; Sloan & Bowe, 2014). Heidegger (1962) focused on the concept of "being." Heidegger viewed phenomenology as the process of scientific inquiry and stated that phenomenology is interpretive in nature. Similar to Husserl, Heidegger asserted the importance of setting aside previous ideas and judgment as the meaning of "being" is explored by the researcher. However, Heidegger did not believe that all previous judgment can be set aside, but also indicated that time is an important factor in interpretive inquiry. Heidegger asserted that the acknowledgment of prior experiences (past, present, and future) is part of the interpretive process of phenomenology. Unlike Husserl, Heidegger did not disavow history and culture but instead saw this as a part of the interpretive process.

Contemporary phenomenological research in the hermeneutic realm is one in which the inquiry is used to identify themes that are extracted from the personal stories of the research participants (Sloan & Bowe, 2014). In this research, I have sought to

interpret the lived experiences and develop the working themes based upon interviews of people who have experienced the phenomena of counseling professionals and their work with adults with ID. From this perspective, I have worked to provide an interpretive analysis of the lived experiences of mental health counselors who have provided counseling to adults with ID. The hermeneutic perspective is derived from the interviews of mental health counselors engaged in counseling with adults with ID and the interpretive framework of capturing the essence of their experiences, since more than one counselor has been interviewed. In turn, the themes that emerged are important in distilling the essence of the combined experiences in order to help others understand the meaning of how mental health counselors experience adults with ID in a counseling setting. I hoped to illuminate the experiences of counselors and, through that interpretive process, offer the profession some insight about how mental health counselors experience this group. This perspective stems from the fact that adults with ID have been receiving limited mental health supports, specifically counseling opportunities (Corbett, 2011; Hemm et al., 2015; Irvine & Beail, 2016; Shankland & Dagnan, 2015). The next section offers definitions of ID, etiology, and prevalence of ID.

Definition of Intellectual Disability

In the *DSM-5*, the APA (2013) defined ID as a long-term cognitive disorder encompassing deficits in adaptive functioning in the domain areas of language (reading, writing, reasoning, knowledge, and memory), social (empathy, social judgment, interpersonal communication skills), and practical skills, which involve self-management and self-care skills (personal care, job responsibilities, money management, community

safety, and school/occupational functioning, etc.; AAIDD, 2017; APA, 2013; Coulter, Buntinx, Craig, & Borthwick-Duffy, 2010; Sadock & Sadock, 2010). ID is typically recognized and assessed during the developmental period as children are falling behind in all above domains. These functional domain deficits may result in the person's inability to meet developmental and social standards for personal independence. ID is a long-term, chronic condition, which frequently co-occurs with a variety of other co-occurring mental health disorders (AAIDDD, 2017; APA, 2013; Charlot & Beasley, 2013; Hemm et al., 2015; Irvine & Beail, 2016). Further, clinical and standardized intelligence testing determines the presence of ID. Assessment of adaptive functioning is an important factor when determining the presence of ID (AAIDD, 2017; APA, 2013). The following subtypes categorize ID: mild, moderate, severe, and profound (AAIDD, 2017; APA, 2013).

Etiology

According to Coulter et al. (2010), the causes or etiology of ID, formerly known as mental retardation, is determined in only a third of the diagnosed cases of ID. The etiology can come from a variety of causes: genetic, physiopathology, illness and injury, or unknown. Genetic conditions can be a precursor for ID and associated with genetic conditions such as Down syndrome and fragile X syndrome (APA, 2013; Coulter et al., 2010; Sadock & Sadock, 2010). Physiological causes of ID are related to birth injury, exposure to toxins in utero or after birth, epilepsy, and medication side-effects (Irvine & Beail, 2016; Sadock & Sadock, 2010). Over a third of the time, clinicians cannot

determine a specific etiology for ID (AAIDD, 2017; APA, 2013; Irvine & Beail, 2016; Sadock & Sadock, 2010).

Prevalence of Dual Diagnosis in Adults with ID

The prevalence of mood disorders in adults with ID can range as high as 25% to 50%, approximately 3 to 4 times greater than the prevalence in the general population (APA, 2000; Brown et al., 2013; Hassiotis, 2002; Irvine & Beail, 2016; McDaniel & Gregory, 2005). Early research indicated a high utilization rate of psychiatric facilities (Matson & Sevin 1994; Sevin, Bowers-Stephens & Crafton, 2003). Additionally, Sing, Sood, Sonenklar, and Ellis (1991) estimated 50% prevalence of mental illness in 50% of institutionalized clients with ID and that 20% to 35% of clients living in the community have an identifiable mental illness. More recent research indicated similar instances of high prevalence rates of mental health disorders. Specifically, Cooper et al. (2007) estimated 40% of adults with ID in Scotland studied presented with co-morbid mental health diagnoses. Bhaumik, Tyrer, McGrother, and Ganghadaran (2008) reviewed psychiatric utilization rates for adults with ID from 2001 to 2006 and found that the there was a high correlation of treatment for mental health disorders and noted an increase of the rates along with the severity of ID. A gender association was noted by Bhaumik et al. The authors distinguished challenging behavior as the most frequently presenting problem in males, while females received diagnoses of schizophrenia, dementia, and depression.

Borthwick-Duffy (1994) asserted considerable difficulty in ascertaining an accurate measure of prevalence due to problems with the consistency variables measured

and sampling procedures, and accordingly, estimated rates are 2 to 8 times greater in comparison to the rates of clients in the general population. Rojahn and Esbensen (2005) conducted a systematic review of existing studies and concurred with Borthwick-Duffy about the myriad of methodological errors in the studies performed, which further complicated the ability to demonstrate the prevalence of mood disorders. Emerson's 2003 study demonstrated empirical evidence of increased risk of mood disorders for adults with ID when compared to the general population.

Reiss and Aman (1997) alluded to an extremely high rate of prevalence of mental health comorbidity based on the high usage of psychoactive drugs of clients with intellectual disabilities. Their study estimated a 45% to 67% rate of psychotropic drug use in developmental institutions. Holden and Gitlesen (2004) asserted that adults with ID represent one of the most overmedicated client demographics. Hurley (2006) and Einfeld et al. (2007) reviewed the literature to look at presenting problems and prescribing patterns of psychotropic medications for clients with ID. Hurley found that depressive disorders and psychosis accounted for the majority of diagnoses in adults with ID. Specifically, the prescribing patterns for adults with ID revealed 32% were prescribed antipsychotics, 28% mood stabilizers, and 27% antidepressants. It is estimated that 35%–48% of clients living in community-based settings are being treated with psychotropic medications (Einfeld et al., 2007; Posey et al., 2005). Mohr and Gray (2007) stated that given the problems of obtaining accurate diagnoses in adults with ID, many experienced adverse, potentially long-term side effects from the widespread use of neuroleptics—which further serves to diminish quality of life. McCabe, McGillivray, and Newton

(2006) estimated that the prevalence of depression is approximately 1 in 10 for adults with ID. Approximately 47% to 57% of adults with ID report symptoms of depression. Rush, Bowman, Eidman, Toole, and Mortenson (2004) asserted that research has demonstrated that clients with ID have 4 to 5 times increased risk for the development of mental illness.

In more recent studies, Bertelli, Rossi, Scuticchio, and Bianco (2015) conducted a meta-analysis of literature about diagnosing psychiatric disorders in adults with ID. After a review of 36 articles meeting their inclusion criteria, the authors concluded that there has been a long-standing neglect of mental health conditions of adults with ID. The authors indicated, as well, a need for more formal guidelines for diagnosis because of the existing challenges in securing an appropriate diagnosis. This further creates a murky picture regarding obtaining accuracy in the prevalence rates of mental health disorders in adults with ID. It is important to review the service systems that have historically provided care to adults with ID to gain greater insight into the specific needs and challenges of adults with ID. This next section reviews the issues related to institutionalization and deinstitutionalization of adults with ID.

Systems of Care and Deinstitutionalization

It is important to note that adults with ID are a very vulnerable group, and many times will need to have life-long support within their communities (Bouras & Holt, 2010). Historically, adults with ID received support in institutional settings (Alba, Prouty, Bruininks, & Lakin, 2007; Bouras & Holt, 2010; Larson et al., 2012; Lemay, 2009). Advocates have argued that inclusion is a concept of exposure to the wider community,

and normalization is advocacy aimed at clients with intellectual disabilities to help them receive the same exposure to and experiences of the community that are afforded to all other citizens (Bouras & Holt, 2010; Frances, Blue-Banning, & Turnbull, 2014; Kim et al., 2001; Landesman & Butterfield, 1987; Lemay, 2009; Taylor, 2001). According to Taylor (2001), the concept of the LRE emerged during the early 1960s as a part of advocacy for clients with mental retardation (MR) and argued that they should receive care in the community rather than segregation in institutions. Proponents of the LRE principle based their arguments on the constitutional principles of due process, equal protection, and liberty (Bouras & Holt, 2010; Frances et al., 2014).

In the 1970s, federal courts began to address the constitutional rights of people with developmental disabilities. This paradigm shift advocated for care in the community, which hailed a series of litigation culminating with the ADA and the Olmstead Act of 1999 (Frances et al., 2014). The Olmstead Act was a Supreme Court decision, which upheld the inclusion and LRE notion that states are required to provide services to clients with mental retardation in the community when qualified ID professionals (QIDP) have deemed that the same or equal care be provided in a community setting (Frances et al., 2014). In essence, individuals with disabilities have a right to community-based living arrangements (Frances et al., 2014). This litigation led to the development of the Home and Community-Based Service Medicaid Waiver options. This waiver provides long-term funding to support adults with ID within their communities and prevents the need for institutionalization (Frances et al., 2014).

Despite the gains in the Federal court system and legislative mandates, the debate about the risks and benefits of community integration continues. Inclusion is a term that has been used to help the community begin to bridge and create resources for persons with ID to live within their community (Dykens, 2006; Frances et al., 2014; Larson et al., 2012). Adults with ID experienced improvements in their quality of life, improved adaptive behavior and gained more choice when supported to live within their communities, versus being institutionalized (Beadle-Brown et al., 2007; Bouras & Holt, 2010; Irvine & Beail, 2016; Koch et al., 2015). However, these gains did not always translate into expanded social networks and community inclusion (Dykens, 2006; Kim et al., 2001; King-Andrews & Farrell, 2006; Lemay, 2009). Additionally, deinstitutionalization did not necessarily decrease challenging behaviors (Irvine & Beail, 2016; Lemay, 2009).

To date, the United States and other countries like Norway, Sweden, and the United Kingdom have accepted the concepts of inclusion and LRE, demonstrated by the observed increase in clients being discharged into community-based care (Beadle-Brown et al., 2010; Beadle-Brown et al., 2007; Bouras, & Holt, 2010; Cain et al., 2010; Dykens, 2006; Kim et al., 2001; Taylor, 2001). Within the United States, there has been a slow acceptance of the inclusive paradigm shift (Bouras & Holt, 2010). Advocacy from the disability community and the Department of Justice (DOJ) occurred when states and localities did not adhere to the LRE as indicated in the Olmstead ruling (Bouras & Holt, 2010). This lack of implementation led to compliance lawsuits against states that had not implemented the LRE and embraced community-based services. From 1971 to 2010, the

number of intellectually disabled residents in state institutions in the United States dropped from 207,356 to 56,813 (Larson et al., 2012). With the movement of clients from institutions into the wider community, adults with ID needed to access services for mental health (Bouras & Holt, 2010; Cain et al., 2010). Many times, adults with ID experienced culture shock when exposed to the community after living for years in institutions (Alba et al., 2007; Bouras & Holt, 2010; Cain et al., 2010; Irvine & Beail, 2016; Rush et al. 2004). Exposure to the freedom of being part of a larger society resulted in problems with the transition into the community (Cain et al., 2010; Corbett, 2011; Bouras & Holt, 2010; Taylor & Knapp, 2013). Among these difficulties are exposure to alcohol and drug abuse, crime, and sexual assault (Cain et al., 2010; Dykens, 2006; Kim et al., 2001; Landesman & Butterfield, 1987; Lynch, 2004; Tomasulo & Razza, 2005). Other problems include bereavement, increased stress resulting from transitions due to living in the community (e.g., increased independence, retirement, and aging), and exposure to violence, exploitation, sexual assault, and substance abuse (Bouras & Holt, 2010; Cain et al., 2010; Clay & Thomas, 2005; Dykens, 2006; Irvine & Beail, 2016; Jahoda et al., 2006; Lynch, 2004; Tomasulo & Razza, 2005).

Virginia Settlement and Deinstitutionalization

I conducted this research in Virginia. Virginia is in the midst of change. In 2008, the Department of Justice (DOJ) launched an investigation to determine if Virginia was adhering to the ADA and the Olmstead mandate. The legislation mandated services within the community that meet LRE. Upon the conclusion of the investigation, the DOJ ruled that Virginia had abandoned its requirement to ensure that adults with ID be served

in the community and indicated that a robust residential community-based system existed, and further indicated that Virginia needed to reduce or eliminate institutionalization. Thus, the DOJ cited Virginia in violation of the ADA and Olmstead agreements (*United States of America v. Commonwealth of Virginia*, 2012). The investigation also revealed that there was an adequate capacity for supporting adults with ID within their communities related to flexible residential and employment supports, and called Virginia to develop more capacity to support adults with ID with mental health needs and provide for the long list of adults with ID waiting for a variety of supports (residential, supported-employment) in the community (*United States of America v. Commonwealth of Virginia*, 2012). Virginia entered into a settlement with the DOJ in 2012, and the tenets of the agreement are still unfolding. Additionally, the settlement agreement required increased implementation of state monitoring to ensure that vulnerable individuals received quality services in the community (*United States of America v. Commonwealth of Virginia*, 2012).

Another identified deficit for community-based care for adults with ID was limited access to adequate mental health supports for individuals with ID transitioning into communities (*United States of America v Commonwealth of Virginia*, 2012). This information is valuable to look at as Virginia continues to move toward deinstitutionalization by the DOJ settlements. Kelly and Su (2015) reviewed effects of the DOJ settlement in the state of Georgia and determined that the rate of psychotropic medication usage increased in the aftermath of transition of adults with ID into the community. This study cited a significant concern related to this increased use of

psychotropic drugs, where no other mental health supports had been employed to assist adults with ID transitioning into the community (Kelly & Su, 2015). It will be important to track research conducted in other states who have transitioned their care from institutional to community-based supports to see the lessons learned as Virginia is in the midst of system change. Due to this system change in Virginia, this research attempts to focus on Virginia's transition and highlight how mental health counselors in Virginia view their experiences with adults with ID in a counseling relationship. I have, also, reviewed some of the factors of importance in understanding the history of how adults with ID have interfaced with mental health service systems.

Diagnostic Overshadowing

Diagnostic overshadowing is a term defined as clinician bias that prevents an adult with ID from receiving a diagnosis of a coexisting mental health disorder that a person with average intelligence with the same symptoms would receive (Reiss, Levitan, & Szyszko, 1982). DO is a problem in that there have been limitations on the quality and type of mental health services offered to adults with ID (Irvine & Beail, 2016; Jahoda, 2016; Jopp & Keys, 2001; Matson & Sevin, 1994). There has been a fleeting effort to address the mental health needs of clients with ID (Arthur, 2003; Dykens, 2006; Fletcher et al., 2007; Irvine & Beail, 2016; Reiss, Levitan, & Szyszko, 1982), due in part to a lack of consistent agreement, until recently, that adults with ID have co-occurring mental illness (Bertelli et al., 2015; Corbett, 2011; Dagnan, Masson, Cavagin, Thwaites, & Hatton, 2014; Irvine & Beail, 2016; Taylor & Knapp, 2013). Supports for adults with ID focused on developing functional skills to live in the community and ignored affective

states related to transitional problems (Irvine & Beail, 2016; Larson et al., 2012). Arthur (2003) and Dykens (2006) asserted that limited research focused on determining the internal affective states of people with ID.

In literature about DO, Jopp and Keys (2001) identified several factors that seem to contribute DO: degree of ID, years of clinician experience, cognitive complexity, and severity and type of psychiatric disorder. Matson and Scior (2004) demonstrated DO in their study with the use of identical scenarios presenting with the same clinical information. Matson and Scior indicated that clinicians did not give a mental health diagnosis to adults with ID even though they presented with the same symptoms. Despite literature available about increased prevalence rates of mental health disorders—in some instances ranging from 3 to 5 times—when compared to the general population, adults with ID are least likely to receive a mental health diagnosis (APA, 2000, 2013; Charlot & Beasley, 2013; Fletcher et al., 2007; Irvine & Beail, 2016).

In early research, Reiss, Levitan, and Szyszko (1982) demonstrated the likelihood of DO. The study examined a sample of mental health professionals (n = 74) and concluded that increased years of professional experience seemed to reduce the presence of DO. However, the results did not demonstrate a high statistical significance. Spengler and Strohmer (1994) found that rehabilitation counselors with more experience were less likely to recommend counseling to adults with ID. Similarly, Reiss, Levitan, and Szyszko conducted research with clinical psychologists and clinical graduate students in state facilities, which suggested that the DO stereotype appeared to strengthen over time and related to increased experience in the field. Spengler and Strohmer (1994) explored

clinician cognitive complexity and a clinical preference for working with adults with ID. Cognitive complexity is defined as the ability to view a person and their social behavior in a multifaceted way (Dagnan, Jahoda, & Kilbane, 2013; Hatton & Taylor, 2013; Irvine & Beail, 2016; Taylor & Knapp, 2013). Spengler and Strohmer proposed that increased clinician complexity and population preference would reduce the DO. The study demonstrated a positive correlation between higher clinician cognitive complexity and a lower instance of DO. The preference for working with adults with ID was not a significant variable in the study (Spengler & Strohmer, 1994).

Evidence of DO exists in qualitative inquiries. Specifically, Weiss et al. (2009) conducted research with family members and paid caregivers to determine their experiences when supporting adults with ID—whom frequently experience challenging behavior or mental health crises presenting at the emergency room. The results of the study revealed concerns expressed by families and professional caregivers that mental health issues are often overlooked or discounted by physicians and nurses. The study found that challenging behavior exhibited by adults with ID are viewed as a part of their ID, versus being seen as related to a mental health illness. Additionally, the study found that caregivers felt frustrated that there was a lack of authentic inquiry into the presence of mental health conditions by emergency room physicians. Weiss et al. concluded that emergency room personnel are poorly educated about dual diagnosis in adults with ID. For these reasons, adults with ID are misunderstood, misdiagnosed, and ill-served in regard to meeting their mental health needs. Given that adults with ID have a significant prevalence of the presence of co-occurring mental health disabilities, it is important that

adults with ID are properly assessed for the presence of mental health disorders, and to recognize that DO is a major contributing factor to adults with ID being underserved (Jahoda, 2016; Jopp & Keys, 2001; Mason & Scior, 2004; Reiss, Levitan & McNally, 1982; Tomasulo & Razza, 2006; Taylor & Knapp, 2013).

Mental Health Assessment for Adults with ID

Throughout the literature, there are broad and varying ranges of the prevalence of mental health disorders in adults with ID (Corbett, 2011; Cooper et al., 2007; Hassiotis, 2002; Matson & Sevin, 1994; McDaniel & Gregory, 2005; Taylor & Knapp, 2013). Adults with ID are more susceptible to symptoms of mental illness due to vulnerabilities associated with social isolation and social support, lack of autonomy, and low coping skills, as well as being subjected to poverty, abuse and neglect (Corbett, 2011; Hartley, Lickel, & MacLean, 2008; Hartley & MacLean, 2009; Hastings et al., 2004; Irvine & Beail, 2016; Mahan et al., 2010; Raffensperger, 2009; Taylor & Knapp, 2013; Tomasulo & Razza, 2006).

Irvine and Beail (2016) asserted many factors influencing high rates of mental illness in adults with ID. The factors fit into three categories: social, physical, and cognitive. In the social category, adults with ID frequently have inadequate social supports, poorly developed social skills, a sense of learned helplessness, high maternal and family stress, and a low socioeconomic level (Corbett, 2011; Hastings et al., 2004; Nezu & Nezu, 1994; Rush et al., 2004; Taylor & Knapp, 2013). Among the physical categories, many clients may have expressive and receptive language deficits and increased likelihood of chromosomal abnormalities and metabolic diseases (Hatton &

Taylor, 2013; Morasky, 2007; Prout & Browning, 2011). In the cognitive realm, it is clear that the level of cognition limits the client's ability to learn adaptive skills that help them cope with a changing environment (Gentile, 2015; Hurley, 2006; Irvine & Beail, 2016; Nezu & Nezu, 1994). These factors contribute to difficulties in obtaining mental health diagnoses in adults with ID.

Diagnostic Challenges

As stated above, there are many problems associated with getting accuracy in assessment and diagnosis of mental health disorders in clients with intellectual disorders (Corbett, 2011; Fletcher et al., 2007; Hurley, 2006; Taylor & Knapp, 2013). It seems that, as the level of cognitive disability increases, so does the difficulty in obtaining an accurate diagnosis (Bouras & Holt, 2010; Evans, Cotton, Einfeld, & Florio, 1999; Fletcher et al., 2007; Gentile & Jackson, 2008; Gentile et al., 2014; Glenn, Bihm, & Lammers, 2003; Irvine & Beail, 2016; McBrian, 2003; Morasky, 2007). Specifically, the literature cites three problems with assessment of adults with ID. First, there is disagreement about how to assess adults with ID specifically related to the deficiency of the current diagnostic classification systems (*DSM-IV-TR* and ICD-9). Fletcher et al. (2007) created an international task force to address the concerns related to the current assessment process when relying on a criteria-based evaluation of the *DSM-IV-TR*. This work group developed the *Diagnostic Manual of Intellectual Disability (DM-ID)*. The DM-ID is the culmination of years of work, which seeks to review the evidence-based approaches for the adaptations for diagnostic criteria for adults with ID (Fletcher et al., 2007). Hurley (2006) discussed the presence of mental health disability in adults with ID

and advocated for the use of behavioral equivalents. Behavioral equivalents can be used in place of subjective verbal symptom-based endorsement and confirmed through clinical and caregiver observational data (Charlot & Beasley, 2013; Sturmey, Laud, Cooper, Matson, & Fodstad, 2010). The DM-ID has been updated to correlate with the *DSM-5* changes (NADD, 2016).

Second, there has been considerable discussion within the literature about the lack of research and training for mental health practitioners with adults with ID and co-occurring mental health disorders (Taylor & Knapp, 2013). DO has contributed to many adults with ID not being considered for traditional mental health services, like counseling (Corbett, 2011; Irvine & Beail, 2016; Raffensperger, 2009; Taylor & Knapp, 2013). The majority of mental health intervention has come in the form of outpatient psychiatric services and the prescribing of atypical antipsychotic medications as a first approach to addressing behavioral health crisis in adults with ID (Corbett, 2011). This phenomenon led to a general lack of training and exposure to adults with ID (Corbett, 2011; Tomasulo & Razza, 2006). Weiss et al. (2009) asserted that many medical professionals lack training in dual diagnosis, and thus when presented with a behavioral crisis with adults with ID, the clinician does not view the crisis as psychiatric, but more related to the ID condition.

Finally, the concept of DO may contribute to bias, which ultimately limits an accurate diagnosis of mental health problems in adults with ID (Jopp, 2001; Mason & Scior, 2004). Therefore, DO leads to the continuation of diagnostic challenges in the form of clinician bias (Corbett, 2011; Hatton & Taylor, 2013; Irvine & Beail, 2016; Jahoda,

2016; Jopp & Keys, 2001; Mason & Scior, 2004; McNally & McMurray, 2015; Taylor & Knapp, 2013).

Inadequacy of Current Diagnostic Classification

There are many theories describing the diagnostic problems associated with adults with ID. Several authors have discussed the inadequacy of the *DSM-IV-TR* systems of diagnostic classification when assessing clients with ID (Charlot, 2005; Esbensen, Seltzer, Greenberg & Benson, 2005; Fletcher et al., 2007; Hurley, Levitas, Lecavalier & Pary, 2007; Matson & Sevin, 1994; McDaniel & Gregory, 2005; Rush et al., 2004). Morasky (2007) voiced concerns about the diagnostic system due to the heavy reliance on subjective, verbal reports of symptoms by the client. Researchers asserted that significant problems arise when clients fail to receive accurate diagnoses of mental health disorders because the diagnostic classification systems (*DSM-IV-TR, DSM-5*, and ICD-9/10) require clients to give a verbal report on their emotional states (Hurley, 2006; Irvine & Beail, 2016; McNally & McMurray, 2015; Morasky, 2007; Rush et al., 2004; Taylor & Knapp, 2013).

Researchers have advocated for an adaptation of behavioral equivalents for use in assessing clients with ID because these equivalents are determined by direct observation or reports from caretakers (Charlot & Beasley, 2010; Hurley, 2006). The assessment process looks for behavioral categories for mental health symptoms like sadness, tearfulness, anger, refusal of activities, agitation, fluctuations or extremes in appetite and sleep, psychomotor agitation or retardation (Hurley, 2006). Additionally, observation of excessive fatigue and diminished self-care skills are indicators for mental health disorders

(Charlot, 2005; Charlot & Beasley, 2013; Hurley, 2006). One argument in support of the use of behavioral equivalents is that adults with ID rarely seek mental health services (Hurley, 2006). According to Feldman et al. (2004), adults with ID are typically referred for mental health services by family, teachers, or residential direct care staff who are reporting some degree of challenging behavior (e.g., aggression, self-injurious behavior [SIB], and destruction of property).

Like Feldman et al. (2004), Oliver et al. (2005) looked at the factors that cause direct-care professionals to make mental health referrals for adults with ID. The study found that direct-care professionals frequently made referrals based on externalizing factors like aggression, SIB, and property destruction. This assertion is further supported by Hemmings et al. (2006), who found significant correlations in aggression when 214 clients were screened using the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Moss et al., 1997). Additionally, adults with ID are frequently unable to verbalize or describe internal states and/or reliably report personal or medical history. Concerns for adults with mild ID are less significant, because they can communicate. However, there still are concerns related to adults with mild ID being able to describe the duration and severity of their symptoms (Fletcher et al., 2007; Hurley, 2006; Irvine & Beail, 2016; Jahoda, 2016; Morasky, 2007; Taylor & Knapp, 2013).

Another factor called acquiescence bias involves clients masking their symptoms or attempting to please the evaluator by responding to all questions in a positive manner (Charlot, 2005; Finlay & Lyons, 2002; Fletcher et al., 2007; Morasky, 2007; Rush et al., 2004). Previous research has indicated that there is a high prevalence of psychiatric

illness in adults with ID and that it has not been accurately identified (Corbett, 2011; Fletcher et al., 2007; Hurley, 2006; Jahoda 2016; Jahoda & Markova, 2004). Tsiouris, Mann, Patti, and Sturmey (2003, 2004) asserted that one must be careful not to use what has been deemed as challenging behaviors (e.g., SIB, aggression, screaming, etc.) as behavioral equivalents when attempting to diagnose depression or other mood disorders in adults with ID. Their study did not support the use of challenging behaviors as behavioral equivalents or indicators for the existence of depression in clients with intellectual disabilities. Instead, clinicians should rely on the core diagnostic criteria for depression as indicated in the *DSM-IV-TR* (Fletcher et al., 2007; Hurley, 2006; Sturmey et al., 2010).

There is considerable debate related to behavioral measures as substantial indicators for the presence of symptoms related to a defined mental health disorder. Specifically, Sturmey et al. (2010) asserted that challenging behaviors (aggression, property destruction, and self-injurious behavior) cannot be used to identify mental health disorders specifically without verification of structured interviews, along with the use of psychometric screening instruments. Within the last few decades, there has been considerable research completed regarding screening tools. The Aberrant Behavior Checklist (Aman, Singh, Steward, & Field, 1985), the Psychopathology Instrument for Mentally Retarded Adults (Kazdin, Matson & Senatore, 1983), Diagnostic Assessment of the Severely Handicapped (Matson, Gardner, Coe & Sovner, 1991), and Assessment of Dual Diagnosis (Esbensen, Rojahn, Aman & Ruedrich, 2003) are psychometrically sound instruments and are commonly used in research (Bertelli et al., 2015; Irvine & Beail,

2016; Matson & Shoemaker, 2011; Taylor & Knapp, 2013). Although screening tools are meant to augment a sound clinical interview, it is unclear how often these tools are being used to determine a diagnosis in adults with ID by mental health professionals (Bertelli et al., 2015; Charlot & Beasley, 2013).

The Diagnostic Manual for Intellectual Disability: A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID) was developed by the National Association for Dual Diagnosis (Fletcher, 2011). THE DM-ID is designed to guide for the successful adaptation of criteria (behavioral and collateral information), and a source for evidence-based information on each diagnostic category, and also to offer guidance on how to accurately assess for the presence of mental health disorders in adults with ID (Fletcher et al., 2007). When the *DSM-5* was updated, the National Association of Dual Diagnosis (NADD) updated the DM-ID to correlate the changes in the *DSM-5* (NADD, 2016).

More recently, Bertelli et al. (2015) conducted a review of international literature (n = 36) to determine the current issues with diagnosis, and to determine if there are any specific and effective methodologies being utilized to detect the presence of mental health disorder for adults with ID. The authors acknowledged problems related to DO, and high and wide variances in prevalence rates for adults with ID and cited that no definitive process has been defined. They cite problems related to the identification of psychiatric symptoms, use of behavioral equivalents, assessment, diagnostic criteria and screening tools with adults with ID. Bertelli et al. cited the work of the Royal College of Psychiatrists in the United Kingdom, and NADD in the U.S. for their work in the

development of the *Diagnostic Criteria for Learning Disability* (DC-LD; Royal College of Psychiatrists, 2001) and the DM-ID (Fletcher et al., 2007). The authors cite that more improvements are needed to improve the reliability and accuracy of diagnosis in adults with ID.

Psychotropic Medication Usage

Adults with ID are among the most medicated populations in our society (Crossley & Withers, 2009; Deb et al., 2009; Deb et al., 2015; Gentile & Jackson, 2008; Tsiouris et al., 2012; Ulzen & Powers, 2008). Research has indicated that adults with ID are heavily medicated with antipsychotic medications and are rarely treated as a response to a specific diagnosis (Crossley & Withers, 2009; Ulzen & Powers, 2008). Instead, adults with ID are treated to address challenging behaviors. The working definition of challenging behaviors as described by Deb et al. (2015) is socially unacceptable behavior that limits a person's value in the community. The behavior creates distress, property damage, harm or disadvantage to the person or others, and usually requires some intervention for safety. There are several themes within the literature related to the use of psychotropic medications in adults with ID. The topics are as follows: heavy drug usage specifically related to antipsychotics (Crossley & Withers, 2009), no formal mental health diagnosis associated with the use of antipsychotic medication (Crossley & Withers, 2009; Posey et al., 2008), poorly managed side-effects (Bouras & Holt, 2010; Mahan et al., 2010; Siddique, Chung, Brown & Miranda, 2012), and minimal rigorous studies to support the widespread usage of psychotropic drugs with adults with ID (Crossley & Withers, 2009; Deb et al, 2015; Irvine & Beail, 2016; Posey et al., 2008).

Crossley and Withers (2009) conducted a qualitative grounded theory study examining the widespread use of psychotropic medication among adults with ID. The research indicated that there was a widespread use of atypical antipsychotic medications prescribed predominately to control challenging behaviors where there was no formalized mental health diagnosis. Crossley and Withers interviewed eight adults with ID, which revealed that the respondents had little understanding about the purpose of the medications or the potential side-effects. Adults with ID experienced a reduction in their quality of life due to poor understanding and inability to accurately report side-effects (Crossley & Withers, 2009).

Ulzen and Powers (2008) cited a heavy use of psychotropic medications for adults with ID. Their research focused on efforts to understand position rationale for the prescription of atypical antipsychotic medications. The methodology focused on understanding a justification for prescribing psychotropic medications and determined that physicians do use methods for their prescribing practices and identified three areas of explanation: target symptoms, illness, and behavioral psychopharmacological approach. Data collection on 87 individuals residing in a state institution and the conclusions indicated a primary-illness approach as the most common rationale for prescribing. The authors recommended a more robust process for documenting the rationale for prescribing the medications.

Singh and Matson (2009) and Deb et al. (2009) conducted research that supports assertions about the heavy use of psychotropic medication among adults with ID and cite the lack of research in which random controlled trials (RCT) are identified in

investigating the efficacy of using psychotropic medication to control challenging behaviors. Of the RCT studies conducted, many demonstrate methodological concerns related to small samples, lack of informed consent, poor controls, etc.

Posey et al. (2008) suggested a need for more studies specifically looking at the prevalence related to long-term use of atypical antipsychotics in adults with ID and autism. The authors noted that the use of atypical antipsychotics for lengthy periods may cause metabolic syndrome (development of diabetes) and weight gain—which is linked to a reduction of health and quality of life. Other concerns related to increased risk of extrapyramidal symptoms like drooling, dystonic reactions, and tremors, are important health considerations to monitor.

Caregivers refer adults with ID for services due to problems such as aggression, property destruction and self-injurious behavior (Bouras & Holt, 2010; Feldman et al., 2004; Florez & Bethay, 2017; Hurley, 2006; Oliver et al., 2005). Donley et al. (2012) conducted research to determine caregiver knowledge and understanding of the use of psychotropic medications. The study concluded that caregiver knowledge was minimal, which contributed to the unwarranted use of psychotropic medication and resulted in failure to recognize for side-effects. As caregivers are positioned to offer feedback to physicians regarding the effectiveness of the medications, a lack of education about the intended effects and side-effects will directly impact the health, safety, and quality of life for adults with ID in their care.

Need for Training and Rigorous Research

The lack of accurate diagnosis of psychopathology is connected to the lack of evidenced-based research and training. Borthwick-Duffy (1994) initially suggested that much of the research conducted in related outcome studies was single-case design or had significant methodological flaws (small sample sizes, lack of clear diagnostic criteria, lack of randomized controls) within the designs. With a lack of research, there is a lack of development of training for mental health clinicians to identify and meet the needs of adults with ID. The lack of research has led to assertions that adults with ID have been underserved and poorly served (Reiss, Levitan, & McNally, 1982; Tomasulo & Razza, 2006). Charlot and Beasley (2013) and Dagnan et al. (2013) expressed concerns regarding the lack of empiric research about co-occurring psychopathology, treatment, and interventions, and the lack of empiric research related to much of the current literature cites a general lack of empirical research about co-occurring psychopathology (Charlot & Beasley, 2013; Dagnan et al., 2013; Hassiotis, 2002; Jahoda et al., 2006; Taylor & Knapp, 2016).

In an effort to identify trends in training to address the mental health needs of adults with ID, Hemm et al. (2014) conducted a mixed-methods review of literature to identify the perceived needs as identified by health care professionals when working with adults with ID. This study focused on the system of care in the United Kingdom. The United Kingdom, not unlike the United States, has a history of specialized care for adults with ID. However, there is a paradigm shift to ensure that there is no discrimination and to allow for mental health services to be addressed by mainstream health care

professionals. This shift in service provision was meant to help adults with ID receive care in the communities of their choice and not be limited to locality based upon access to health care. Hemm et al. conducted an exhaustive review of the literature seeking to extract themes about the perceptions of mainstream health care providers (nurses, counselors, general practitioners, psychiatrists, and psychologists) as they worked with adults with ID. The study identified three main themes. First, general communication was deemed a concern expressed by the clinicians due to verbal limitations of adults with ID. This was identified as a major concern related to understanding what the needs are as expressed by the person presenting for care. Second, the clinicians expressed a lack of training about the disability itself. A subtheme was the ability to connect on a consultation basis with other professionals who were more versed with and exposed to adults with ID. Lastly, specific disciplines related to assessment, diagnosis, intervention, and management of health (physical and emotional) related to adults with ID was an identified training need. Hemm et al. also commented that clinician bias and negative attitude was a significant factor in their meta-analysis.

Viecili, MacMullin, Weiss & Morin (2010) conducted a survey analysis of Canadian psychology graduate students (counseling psychology, neuropsychology) and looked for predictors of interest in working with adults with ID. The authors reviewed literature that suggested that there are limited professionals providing care for adults with ID and other developmental disabilities (DD). Additionally, there is limited research that examines the career pathways that lead students and professionals to become interested in working with the ID/DD client demographic (Viecili, MacMullin, Weiss & Morin, 2010).

Viecili et al. identified that slightly more than half of the students surveyed predicted future work with individuals with DD. The study concluded that students with formal coursework and formal training in assessment and integrated exposure (volunteering, practicum and internships) to individuals with DD greatly enhanced the openness of the student to working with the population.

In the last 20 years, there has been an increase in the research literature about assessment, treatment, and quality of life regarding adult with ID residing in the community (Corbett, 2011; Irvine & Beail, 2016; Raffensperger, 2009). However, much of the research is case study and limited to single-design research (Charlot & Beasley, 2013; Irvine & Beail, 2016; Jahoda, 2016). In order to increase the rigor of the evidence base, it is necessary to conduct random controlled trial research (Bouras & Holt, 2010; Singh & Matson, 2009). Without such research, clinicians lack well-defined information about how to accurately diagnosis and treat mental health disorders in adults with ID (Borthwick-Duffy, 1994; Butz, Bowling, & Bliss, 2000; Costello et al., 2010; Fletcher et al., 2007; Hassiotis, 2002; Jahoda et al., 2006; Matson & Sevin, 1994). Additionally, little research effort has been made to operationalize affective states of adults with ID (Arthur, 2003; Corbett, 2011; Dykens, 2006; Irvine & Beail, 2016). During the last 30 years, there have been some studies that attempted to measure internal affective states of adults with ID (Dykens, 2006)—which have been thought to be critical to advocacy efforts to determine quality of life measures for adults with ID (Arthur, 2003; Dykens, 2006; Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005). Specifically, Green and Reid (1996) attempted to measure indices of happiness (e.g., smiling and laughing) and depression

(crying, frowning, and grimacing) when compared to caregivers' ratings. This research provoked several more studies, in an effort to replicate Green and Reid's study, in order to generate more information regarding how these indices are used to determine changes in mood states and the assessment of psychopathology (Green, Gardner, & Reid, 1997; Green & Reid, 1999). These studies provided evidence that affective states in adults with ID can be measured reliably and with validity. Knowledge gained regarding internal states can help clinicians working with adults with ID to get a better measure for how to determine mood states and changes as they relate to treating mental health disorders and determining treatment outcomes. It is necessary to recognize the relationship between assessment, measurement of affective mood states, and diagnosis in adults with ID to help with identifying how to train mental health counselors to assess adults with ID accurately. The lack of interest or research and understanding of the affective needs lends to the theory of DO and the lack of research inquiry into the specific emotional and mental health needs of adults with ID (Mason & Scior, 2004). The lack of inquiry leads to the lack of defined training of mental health counselors to meet the needs of adults with ID (Costello et al., 2010; Drucker, 2011).

Costello et al. (2010) asserted that few studies exist to examine the effectiveness of training programs for the provision of mental health services to adults with ID. Training is recognized as essential to the development of consistent, ethical, and evidence-based application of theory and provision of mental health services (Costello et al. 2010; Drucker, 2011). Graham, Herbert, Price, and Williams (2004) explored the perceptions of psychiatry interns working with adults with ID. The study identified that

the interns felt underprepared to work with adults with ID. Additionally, the interns expressed feelings of isolation and lacked a peer group. The lack of a peer group offered no venue for discussions regarding concerns about competency and preparedness to treat the complex needs of adults with ID. Drucker (2011) asserted that when supervising interns working with adults with ID, after adjusting for the unique needs of working with adults with ID, the supervision process is similar to any other clinical supervision. Drucker acknowledged that adults with ID are currently underserved due to the lack of formal training programs and that, given the increased prevalence of co-morbid mental health issues that are seen in adults with ID, more training programs are a necessity. I did not locate any studies investigating training or the experiences of counselors working with or related to training about adults with ID.

The development of professional organizations helped to recognize the need for increased training and emphasis of clinicians to address the mental health needs of adults with ID in the community (Drucker, 2011). The National Association of Dual Diagnosis (NADD) is one such organization that has a mission to research and promote information about the effective treatment of mental health and well-being of adults with ID in the community (NADD, 2016).

There is a significant lack of clinical training opportunities and clinical education regarding the specialized needs of adults with ID, which contributes to the lack of services available to this client demographic (Cain et al., 2010; Corbett, 2011; Hassiotis, 2002; Hurley et al., 2007; Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007; Matson & Sevin, 1994; McCabe et al., 2006; Tomasulo & Razza, 2006). With less mental health

professionals (psychiatrists, psychologists, etc.) working with adults with ID, the bulk of clinical attention has been in the form of referral and treatment by outpatient psychiatry and the use of psychotropic medications.

Counseling for Adults with ID

Historically there has been a lack of counseling options offered to adults with ID. Bender (1993) characterized this lack of interest in adults with ID as being an "unoffered chair," as a description of therapeutic disdain (p. 8). Therapeutic disdain relates to the concept of DO, which asserts that adults with ID present with challenging behaviors and do not possess the skills needed to participate in counseling (Oathamshaw & Haddock, 2006; Reiss, Levitan, & McNally, 1982; Taylor & Knapp, 2013).

Adults with ID are currently able to live within the community, versus institutional settings, due to the paradigm shift toward community-based supports (Bouras & Holt, 2010; Larson et al., 2012; Lemay, 2019). Adults with ID have significant mental health vulnerabilities and greater risk for stress as compared to the general population (Corbett, 2011; Fletcher, 2011; Fletcher et al., 2007; Irvine & Beail, 2016). Counseling is an extremely helpful and preventive intervention. Professional counseling focuses on a wellness perspective to help individuals promote and heal from psycho-social stressors (Seligman, 2006). However, there is a distinct lack of counseling offered to adults with ID within their communities (Bender, 1993; Corbett, 2011; Irvine & Beail, 2016; Raffensperger, 2009; Taylor & Knapp, 2013). Research suggests that counseling interventions can be effective in remediating mental health distress for adults with ID (Brown et al., 2013; Clute, 2010; Dodd et al., 2013; Florez & Bethay, 2017; Nicoll et al.,

2013, Oathamshaw & Haddock, 2006). When working with adults with ID, it is important to consider the level of cognitive functioning, presenting problems related to the referral, a comparison of how the current symptoms and stressors cause a departure from their baseline behavior and functioning level, and what skills and strengths are noted in the client (Brown et al., 2013; Charlton & Dykstra, 2011; Jahoda, 2016; Morasky, 2007; Taylor & Knapp, 2013). Some specific therapy adaptations are using multiple modalities of presenting information (visual, auditory, kinesthetic) and using language that is understood by the individual. Additionally, repetition, role play, being directive with clients, not making assumptions that client may be able to generalize their skills to other areas are helpful with adults with ID in a therapeutic relationship (Charlton & Dykstra, 2011; Jahoda, 2016; Morasky, 2007; Taylor & Knapp, 2013). Psychodynamic and cognitive-behavioral therapeutic approaches are addressed to offer insight into how these methods are used with adults with ID.

Psychodynamic

Beail and Jackson (2013) cited the origins of psychodynamic therapy literature with adults with ID literature dating back to 1980s. Like other types of therapeutic interventions, therapy adaptions for adults with ID are documented (Morasky, 2007). Beail and Jackson (2013) asserted that some of the adaptations are being able to work without a clear statement of the problem from the adult with ID, because caregivers or family typically refer adults with ID for treatment interventions. Part of the reason that adults with ID are not aware of the presenting problem is that they are not self-referring but instead are referred by caregivers or family due to property destruction, aggression,

and self-injurious behavior (SIB). Adults with ID rarely understand why they are referred for mental health treatment. Since there is not a clear understanding about why they are referred, it makes it even harder to obtain a clear statement of the problem requiring intervention. Dagnan et al. (2013) explored the factors to be considered when preparing adults with ID for therapy and found that adults with ID are frequently not informed about the option for therapy and if referred do not understand the purpose of therapy. However, when adults with ID understand and can identify the reasons for seeking mental health counseling, they can quickly progress and explore their concerns about their problems during the therapy experience (Beail & Jackson, 2013; Jahoda, 2016; Newman & Beail, 2010).

Psychodynamic therapeutic approaches may be a good fit for adults with ID due to relational focus, high degree of therapeutic alliance, attending to affect and emotional expression, fantasy, and focus and attention of patterns of early relational experiences, which seem to lend to positive attributes (Beail & Jackson, 2013; McInnis, 2016). Newman and Beail (2010) proposed that adults with ID when offered a choice seemed to prefer psychodynamic approaches when compared to CBT or applied behavioral analysis (ABA) therapies. Additionally, Beail, Kellett, Newman, and Warden (2007) explored the dose-effect of psychodynamic therapy, or the number of treatment sessions needed to produce a positive result, when comparing three groups of adults with ID with mental health problems receiving different lengths of therapy. The results indicated that most gains in therapy were demonstrated within the first eight sessions. This supports previous outcome research that suggested that adults with ID can benefit and have positive results

from therapy interventions (Jahoda, 2016; McInnis, 2016; Prout & Browning, 2011; Prout & Nowak-Drabik, 2003; Willner, 2005).

Newman and Beail (2010) offered that adults with ID are capable and use a broad range of defense mechanisms. The Defense Mechanism Rating Scales developed by Perry (1996) are designed to detect and rate 28 defense mechanisms from most-mature to least-mature. Newman and Beail (2010) identified that adults with ID were able to demonstrate 24 out of the 28 defenses recognized in psychodynamic theory. There is evidence that adults with ID when properly prepared for therapy can benefit from psychodynamic approaches to therapy and may seem to prefer this modality.

More recently, McInnis (2016) offered a meta-analysis of literature about the psychodynamic counseling interventions. In this research, McInnis concluded that there is evidence that psycho-dynamic counseling interventions are supportive with adults with ID and appear to enhance well-being, reduce emotional and behavioral dysregulation, increase protective psychological coping skills, and individual growth. Shepherd and Beail (2017) conducted a meta-analysis of psychoanalytic and psychodynamic literature to determine the quality of the literature presented. The study concluded that while there is emerging evidence of the efficacy of psychodynamic counseling interventions with adults with ID, several methodological concerns are present within the literature that reduce the rigor of the studies reviewed, thus casting a shadow on the quality of the research conducted.

Cognitive Behavioral Therapy

Within the general population, there are some studies that demonstrate that CBT is effective in treating a wide array of mental health problems (Hollon, 2015; Jahoda, 2016; Kuyken, Dalgleish & Holden 2007; Lindsay, Stenfert-Kroese & Drew, 2005; Unwin et al., 2016). The gold standard for reviewing literature is a meta-analysis (Hollon, 2015; Unwin et al., 2016). There is a large body of rigorous studies including meta-analysis research related to the efficacy of CBT for the general population (Hoffmann & Smits, 2008; Hollon, 2015; Hunot, Churchill, Silva, & Teixeira, 2007; Kuyken et al., 2007; Linardon, Wade, de la Piedad Garcia, & Brennan, 2017). There are studies that cite the efficacy of CBT when working with adults with ID (Barrowcliff, 2008; Brown & Marshall, 2006; Bruce, Collins, Langdon, Powlitch, & Reynolds, 2010; Corbett, 2011; Jahoda, 2016; Lindsay et al., 2005; Nicholl & Beail, 2013; Unwin et al., 2016). However, many studies expressed concerns about validity and reliability of psychometric assessment tools, and the lack of rigor in single-case studies as a primary methodological research (James, 2017; Stott, Charlesworth, & Scior, 2017; Unwin et al., 2016).

CBT for Anxiety

Lindsay, Willner, and Sturmey (2013) explored CBT interventions with adults with ID and determined that there is evidence that with adaptations CBT can be effective in treating adults with ID for anxiety disorders. Many of the studies are reviewed were single-case studies, and there was a lack of rigorous randomized controlled studies available for review. Before therapy initiation, adults with ID will be assessed and prepared for therapy, and they will be informed of client and therapeutic relationship,

expectancy, and techniques (Hatton & Taylor, 2013). In single-case designs assessing CBT interventions addressing anxiety, it is important to note that elements of Beck's cognitive therapy are adjusted and simplified to support adults with ID. One main variation is the recognition that social stigma is related to increased psychopathology in adults with ID (Brown et al., 2013; Dagnan & Warring, 2004; Irvine & Beail, 2016; Thwaites & Dagnan, 2004). Some of the modifications are as follows: set an agenda; provide education about mental health disorder, therapy, and CBT interventions; use pre and post assessments (Beck Anxiety Inventory, Beck, Steer & Garbin, 1988; Brief Symptom Inventory, Derogatis & Melisaratos, 1983; Glasgow Anxiety Scale for Intellectual Disability, Mindham & Espie, 2003) to measure symptoms, establish between thoughts and mood (anxiety/depression) symptoms, monitor automatic thoughts and develop a connection to beliefs and schema, test and challenge accuracy of automatic thoughts, generate alternative thoughts frameworks, rehearse during session and involve caregivers to ensure that they can help to remind the client of skills practiced, and give homework (Lindsay et al., 2013). The CBT adaptations for adults with ID to address depression are anecdotal reports for depression and not based on rigorous methodological designs that offer strength in its conclusions (Esbensen & Hartley, 2013; Gaus, 2011; Pert et al., 2013). Like the research presented for depression and other mental health disorders and symptoms (anger), the meta-analysis revealed single-case studies or significant methodological design flaws in much of the research available for review (Esbensen & Harley, 2013; Unwin et al., 2016; Wright, 2013).

Dialectical Behavioral Therapy

Brown et al. (2013) and Charlton and Dykstra (2011) offered adaptations for the use of dialectical behavioral therapy (DBT) for clients with ID. DBT with adaptations is believed to to a good fit for adults with ID. In part, DBT has been widely associated with positive treatment outcomes for clients with chronic behavioral problems and vulnerability to stress, and it is helpful to clients who present with a need for intensive and long-term interventions (Baillie & Slater, 2014; Brown et al., 2013; Charlton & Dykstra, 2011). In many ways, adults with ID present similarly in terms of the intensity and chronic nature of mental health disability, like individuals presenting with borderline personality disorder (Brown et al., 2013; Charlton & Dykstra, 2011; Corbett, 2011). Brown et al. and Charlton and Dykstra (2011) asserted that adults with ID are very responsive to working on the skills training and skills-training format. The skills training is a great format for adults with ID because it teaches skills that have not had much development (emotional recognition, regulation, mindfulness, acceptance, and social skills, etc.; Baillie & Slater, 2014; Brown et al., 2013; Charlton & Dykstra, 2011; Lew, 2011; Linehan, 1993). Brown et al. conducted a longitudinal 4-year study using an adapted skills system from DBT interventions. In this study, the authors worked with 40 adults with ID with co-occurring mental health disorders and challenging behaviors (aggression, self-injury, property destruction, and sexual offending, etc.) in to receive weekly individual adapted DBT and weekly DBT Skills training. The results revealed a statistically significant reduction in challenging behaviors to the majority of the participants in the study. Baillie and Slater (2014) offered a 4-year study about DBT

skills in a community mental health program serving adults with ID. In this study, the authors indicated that they had less success with a format that was not contingent on life experiences that clients could relate to, so they adopted a community learning model to help with more generalization of skills. The authors concluded that adapted DBT skills are an important component in community-based supports for assisting adults with ID to develop skills for reduction of challenging behaviors, but admitted more research is needed to determine specific evidence-based practices.

Mindfulness Psychotherapy

Mindfulness-based therapies have gained considerable research efficacy and are practical, cost effective and offer clinical value when integrated within the counseling relationship (Kabat-Zinn, 1990; Singh, Lancioni, Winton, et al., 2013). Mindfulness interventions are within the constructs of CBT. The mindfulness strategies of Buddhist meditational strategies of enhanced awareness and acceptance are blended into CBT as the basis to impact psychosocial functioning (Singh, Lancioni, Winton, et al., 2013). Mindfulness interventions adapted for adults with ID offer the ability to develop individual autonomy and self–regulation in a tangible way that allows the person to manage mental health symptoms (Robertson, 2011). Interventions using mindfulness techniques include teaching personal meditation, behavioral practices (loving, kindness, and compassion exercises), empathy, and cognitive activities of acceptance of feelings and sustaining attention (Robertson, 2011). Mindfulness strategies are effective for anger (Singh, Wahler, Adkins, & Myers, 2003), sexual offenders (Singh, Lancioni, & Winston, 2008), aggression (Singh, Lancioni, Karazsia, et al., 2013), Prader-Willi syndrome, and

obesity (Singh, Lancioni, Singh, et al., 2008). Leoni, Corti and Cavagnola (2015) suggested that interventions like mindfulness, acceptance commitment therapy (ACT) and DBT are part of the third-generation wave of CBT interventions designed to assist individuals with obtaining wellness. The authors suggest that recommended randomized controlled studies to explore the mechanisms that seem effective of adults with ID and hone in on evidenced-based strategies that can be replicated. As with other aspects of CBT research studies, there are limited randomized controlled studies. There is a theme in the research that suggests that CBT interventions do not meet the rigor of research standards, citing randomized research method designs. More research is necessary to meet the standard.

Effectiveness of Counseling Interventions with Adults with ID

Nezu and Nezu (1994) suggested that counseling or psychotherapy is an effective intervention for adults with ID receiving supports within the community. Nezu and Nezu cited limited information about what types of psychotherapeutic interventions were helpful and cited the need for more research to understand what if any therapy interventions were helpful to adults with ID.

Butz et al. (2000) offered review of 30 years of research where they cited major concerns about the lack of investigation regarding therapeutic interventions with adults with ID and suggested that one barrier to understanding how interventions could be helpful to adults with ID was that the treatment systems for habilitation and treatment of emotional/behavioral health needs are not integrated. Butz et al. attributed DO as a reason for a lack of research into understanding whether adults with ID could benefit from

therapy interventions. Another barrier was the separation of the systems of care for adults with ID. Specifically, adults with ID were treated to address medical and habilitative needs related to their functioning. The concept of DO viewed as behavioral distress and attributes behavior to their ID limitations, versus affective or other emotional distress (Reiss, Levitan & McNally, 1982; Taylor & Knapp, 2013).

Prout and Nowak-Drabik (2003) offered a comprehensive review of literature about mental health treatments for adults with ID from 1968 to 1998. This study encompassed 92 studies using an expert consensus model to provide more rigor as much of the literature reviewed did not meet the meta-analysis procedural standard used today. This study found that the majority of studies reviewed met the moderate effectiveness standard outlined by the expert consensus model used to examine the literature. The study concluded that the interventions in psychotherapy were useful and beneficial to adults with ID receiving CBT, DBT, and psychodynamic therapies. Vereenooghe and Langdon (2013) conducted a meta-analysis of psychological therapies in adults with ID. They reviewed 143 studies in their analysis and included some of the interventions previously excluded by Prout and Nowak-Drabik (2003) as they met the "well-established psychological principles and techniques aimed at the prevention and treatment of emotional, behavioral or mental problems" (pp. 40–87). Vereenooghe and Langdon, when exposed to the reviewed studies for psychotherapeutic interventions, concluded that there was moderate positive effect on adults with ID. The authors noted that in many cases CBT was deemed moderately effective for the treatment of depression and anger, and also noted that individual therapy was more effective than group therapy. Unwin et

al. (2016) offered a meta-analysis the literature available about the effectiveness of CBT for anxiety and depression for adults with ID. The authors reviewed 223 studies and identified that 11 of the studies met the meta-analysis inclusion criteria. This further suggests that the research available is lacking in current design rigor allowing for adequate determinations about the evidence-based practices and the global utility of CBT for adults with ID. However, the authors did conclude that there is reasonable evidence that CBT interventions are beneficial about and found similar concerns related to the rigor of research available but found that there was a positive perception of qualitative studies about caregiver and client perceptions of the benefits of CBT as a therapeutic intervention.

This study, like many others, called for much more rigorous research from community-based mental health agencies, due to more adults with ID supported within the community. Sturmey (2005) vigorously criticized the Prout and Nowak-Drabik study, citing that their definition of psychotherapy was a broad version of applied behavioral-analysis (ABA) interventions—thereby not constituting counseling or therapy, per se. Sturmey argued that ABA is an effective intervention for adults with ID, and should not be confused with psychotherapy interventions, thus calling the results of the expert consensus into question. Other scholars, Beail et al. (2007) and Hurley (2006), counter-argued that ABA interventions fell short in addressing the full range of affective states and presenting problems in adults with ID.

The gap in the literature is in an understanding of the specific experiences of mental health counselors who provide mental health counseling to adults with ID. Corbett

(2011) explored how adults with ID are viewed socially and also suggested the root cause for the lack of services is related to the social constructivist view of disability and has translated in the exclusion of services for adults with ID from members of the psychotherapy community. Corbett asserted that this viewpoint led to social exclusion of adults with ID within their communities and limited access to mental health care. Irvine and Beail (2016) reviewed literature related to the mental health needs of adults with ID. They identified several factors that contributed to exclusion of mental health services to adults with ID. First, Irvine and Beail noted that there was a failure to recognize mental health needs in adults with ID. This is related to social and cultural views about ID and DO, leading to the failure to diagnose mental health disorders in adults with ID. Additionally, Irvine and Beail noted that communication and cognitive limitations significantly limit the ability of adults with ID to communicate their symptoms. Moreover, many adults with ID are not themselves seeking mental health services but, instead, are referred by caregivers. The reasons for referral typically relate to challenging behaviors like property destruction, aggression and self-injurious behaviors. In many cases, adults with ID are viewed as having behavioral challenges and there is no effort to identify true mental health symptoms as the antecedents to the challenging behaviors. Irvine and Beail cite that there are a lack of standardized assessment tools and a lack of specialized training for mental health professionals.

The research reviewed in this study arrives at a consensus concerning the need for enhanced mental health supports for adults with ID. Additionally, it is known that adults with ID are vulnerable to stressors that may lead to mental health difficulties. However,

there are few qualitative inquiries about the specific experiences of mental health counselors providing care to adults with ID. Through the literature reviewed, there were limited qualitative studies found about the subject of how mental health professionals viewed adults with ID. In the exhaustive literature review, I could not identify any studies that offered information about how mental health counselors view their work with adults with ID. Literature is offered that supports the need for enhanced mental health supports, versus relying on psychotropic interventions, for adults with ID. Multiple authors concluded that adults with ID can benefit from specific counseling interventions and that more specific training is needed to bridge the current gap in mental health services for adults with ID.

Literature Informing Design and Methodology

As previously mentioned, qualitative methods, specifically hermeneutic phenomenology, seek to provide a lens to explore the lived experiences of study participants. Denzin and Lincoln (2005) asserted that qualitative research is transformative and offered the following definition of qualitative research:

> Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. The practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative

> researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. (p. 3)

Creswell (2014) asserted that qualitative research is more about process, which begins with exploring a specific worldview or assumption. While exploring the worldview, the researcher begins to study the meaning of the phenomenon through the lens of the participants looking for themes and patterns of data through subject to analysis. As previously indicated in Chapter 2, hermeneutic phenomenology is appropriate for this study because it seeks to understand the specific experiences of mental health counselors working with adults with ID in a counseling relationship. Additionally, there is an identified gap in the literature, observed in the absence of relevant literature seeking to understand how mental health counselors view their work with adults with ID. Hermeneutic phenomenology is the most appropriate research design, as discussed in Chapters 1 and 2, to address the problem of limited understanding in how mental health counselors perceive adults with ID. Adults with ID are frequently not receiving counseling services (Corbett, 2011; Irvine & Beail, 2016) but instead are typically using outpatient psychiatry services and have high utilization rates of acute inpatient psychiatric care (Corbett, 2011; Krahn et al., 2010; Raffensperger, 2009; Weiss et al., 2009). Adults with ID have twice the rate of co-occurring mental health disorders as compared to the general population (APA, 2000, 2013; Bradley & Cheatham, 2010; Corbett, 2011; Irvine & Beail, 2016). Denzin and Lincoln (2005) and Creswell (2014) identified that it is appropriate to use qualitative research about unexplored social problems because it allows the ability to develop an understanding through talking

directly with people. This process allows for richer and more robust information to be derived from how people experience the problem and experience being studied. This study seeks to engage and understand the work of mental health counselors currently working with adults with ID in order to inform other professional counselors and counselor educators about the unique needs of adults with ID in a counseling relationship. For this reason, hermeneutic phenomenology is the most appropriate research methodology to accomplish the study's research question: What are the lived experiences of mental health counselors providing counseling services to adults with ID? Quantitative designs are not able to elicit the rich experiences needed to offer detail and understanding related to the identified research question. I have explored other literature using the hermeneutic phenomenology, as well, as a continued justification for using this qualitative design.

Crain and Koehn (2012) conducted a hermeneutic phenomenological inquiry to understand the lived experiences of counselors providing counseling services to women who had experienced interpersonal partner violence (IPV) to understand the phenomenology of hope. Hope is a very subjective experience and best understood through investing in the hermeneutic phenomenological process to help determine how the concept of hope is translated into the work of counselors and their clients who have experience IPV. Hill (2009) conducted research using a hermeneutic phenomenology to explore the lived experiences of psychologists providing services to clients who were dying. This study explored how psychologists viewed their experiences with dying clients and since this was an emerging research topic, the hermeneutic phenomenological

research design offered more insight and informed future research about the utility of the services being provided in an effort to understand and improve supports to this clinical demographic. Atanasov (2016) used hermeneutic phenomenology to explore the experiences of high school counselors using an ethical decision-making model in their work with high school students with substance abuse diagnoses. This study was effective in helping inform other counseling professionals and educators in regard to how counselors used and experienced an ethical decision-making model when working with students who may be at significant risk of harm. All of these studies offer a common thread in their inquiry in that they all seek to understand social phenomenon from the lens of the people providing mental health services.

Summary

This chapter offered a synopsis of the literature concerning mental health supports and adults with ID. Adults with ID are more vulnerable to the development of mental health disorders because they frequently lack autonomy and experience increased rates of abuse and exploitation (Corbett, 2011; Lemay, 2009; McDaniels & Gregory, 2005; Raffensperger, 2009). Adults with ID experienced increased opportunities for community integration and inclusion. Historically, mental health and ID service systems were separated, and although deinstitutionalization created more opportunities, there were higher costs and vulnerabilities experienced by adults with ID in their communities (Bouras & Holt, 2010; Lemay, 2009). DO contributed to the lack of training of community-based mental health counselors as a result of assumptions that adults with ID are not appropriate candidates for mental health counseling due to their cognitive

limitations (Costello et al., 2010; Jopp & Keys, 2001; Mason & Scior, 2004). This chapter offered a synopsis of the literature about prevalence, etiology, diagnostic challenges, lack of training for mental health counselors, and specific mental health interventions that are effective when working in a counseling relationship with adults with ID. Additionally, this chapter offered a rationale that informed the decision to use hermeneutic phenomenology as a vehicle to gain a greater understanding of the lived experiences of mental health counselors providing counseling services to adults with ID. Chapter 3 identifies the research methods and rationale for the study.

Chapter 3: Research Method

The purpose of this qualitative hermeneutic phenomenological research was to understand the lived experiences of counselors working with adults with ID. This research has increased understanding in how counselors work with adults with ID, and increased understanding of these experiences will help to highlight barriers contributing to the lack of counseling services offered to this vulnerable population. Additionally, this research has improved understanding of the current needs of adults with ID as defined by counselors who currently work with ID clients. Increased understanding of the lived experiences of counselors engaged in a counseling relationship with adults with ID could aid in identifying information that can be shared with counselor educators and the wider professional community relating to the specific needs of adults with ID as they engage in a counseling relationship. Furthermore, I sought to identify counselor competency strategies needed when working with this client demographic. As counselor competencies are revealed, it is hoped that the information will be shared with the professional body and help to facilitate increased access to mental health counseling services for adults with ID. This chapter introduces the purpose of the research and offers information about how this research will fill a gap in knowledge. I provide herein the research question, explanation of the research rationale, theoretical lens, and my role as the researcher. Lastly, I outline the methodology as to the participants, recruitment strategy, data analysis plan, and trustworthiness.

Research Design and Rationale

This study is a qualitative hermeneutic phenomenological inquiry using a social constructivist lens to explore the lived experiences of mental health counselors working in a counseling relationship with adults with ID. Hermeneutic phenomenology is a process of qualitative methodology that seeks to explore worldviews and lived experiences (Moustakas, 1994). As such, the constructivist lens helps the researcher explore the rich detail of the participant counselor's reality and how the counselor makes meaning of the experiences that occur (Schwandt, 2000). In this manner, this inquiry allows for a rich and diverse variety of descriptions relating the lived experiences of mental health counselors, detailing their interpretation of the work with adults with ID. Understanding how mental health counselors experience working with adults with ID through multiple frames of reality was the goal of the inquiry.

Adults with ID are a vulnerable group in our society. The literature demonstrated that adults with ID experience a higher prevalence of mental health disorders as compared to the general population (Corbett, 2011; Hurley, 2006; Raffensperger, 2009). Adults with ID are infrequently referred to receive mental health counseling, despite being heavily medicated with psychotropic medications with a lack of accuracy in diagnosis (Crossley & Withers, 2009; Singh & Matson, 2009). It is important to derive an understanding of mental health counselors working with adults with ID in a counseling relationship, specifically because of the need to increase mental health counseling services to adults with ID (Corbett, 2011; Irvine & Beail, 2016). Creswell (2014) offered a variety of qualitative design methods that allow the researcher to develop a deeper

understanding of the lived experiences of the people studied. Creswell defined the main types of qualitative research as narrative, ethnography, case study, grounded theory, and phenomenology. Through an analysis of these subtypes of qualitative research, I concluded that phenomenology, specifically hermeneutic phenomenology, was the best research vehicle for use in understanding the lived experiences of mental health counselors providing counseling to adults with ID. Specifically, phenomenology seeks to understand the meaning that individuals make of a specific phenomenon (Moustakas, 1994). Hermeneutic phenomenology focuses on multiple participant perspectives and can provide a deep and vivid description by which to glean the essence of a lived experience. Mental health counselors are inherently best positioned to offer a description of their experiences of working with adults with ID in a counseling relationship. My hope was that this research will inform the wider profession with respect to working with adults with ID in a counseling relationship.

Role of the Researcher

Qualitative research seeks to create an in-depth understanding of a phenomenon and offers the ability to view how a particular group of people experience that phenomenon (Seidman, 2013). In hermeneutic phenomenology, the researcher is the primary instrument of recruitment and is responsible for interviewing, data collection, coding, and analysis (Creswell, 2014; Patton, 2015). As such, it was important to examine my lens to ensure that I was disclosing and considering all of my experiences and biases as I worked through attempting to understand the lived experiences of mental health counselors.

Positionality

I have a professional identity as a licensed professional counselor. In addition, I am a human services administrator in a nonprofit organization that provides residential supports to adults with ID in the community. Since its inception in 1979, our organization has served 120 adults with ID in the Richmond metro community. I have served this organization for 17 years, and prior to this position I worked in the field for 12 years in various mental health support positions. In my role as a human service administrator, I am responsible for the plan of care for the individuals we support. In assessing individual needs related to a plan of care, it is often necessary to link adults with ID to mental health counselors due to life problems related to anger, depression, grief, and loss. My experience has been that it is difficult to find mental health counselors willing to take adults with ID on in a counseling relationship. Much of what I hoped to learn was how mental health counselors perceive adults with ID as recipients of counseling services. There is an identified gap in the relevant literature, exhibiting a conspicuous lack of information on the experiences of mental health counselors working with adults with ID. Given my life experience, I have managed possible biases through the use of a field journal in which I have bracketed information to ensure that I have separated my perceptions from those of the participants in the study. Patton (2015) described bracketing as a process of viewing information in the purest form, searching for the meaning of the information by not allowing the information presented to be interpreted through a common knowledge lens. Instead, the researcher seeks the meaning of the

information from the lens of the person experiencing it, attempting to qualify the experience in rich, thick detail (Moustakas, 1994; Patton, 2015).

Methodology

I conducted the bulk of the research in Virginia. Virginia is experiencing a systemic change in relation to the closure of institutions and transitioning to offering of services and supports in the LRE manner (*United States of America v. Commonwealth of Virginia,* 2012*)*. With the challenge, the community is the primary focus of support for adults with ID. The review of literature underscored problems with the lack of mental health counseling and an overreliance on outpatient psychiatry and psychotropic medications. This is despite literature that suggested CBT, psychodynamic, and mindfulness psychotherapy are effective in the treatment of adults with ID. Given this information, there are still very few mental health counselors providing care to adults with ID in a counseling relationship.

The design was a qualitative inquiry to understand the lived experiences of mental health counselors who have engaged in a counseling relationship. Increased understanding of the experiences and beliefs of mental health counselor will offer insight to the wider profession in the hopes of increasing knowledge about how best to serve adults with ID.

Sampling and Participant Selection

An e-mail was sent to the Virginia Chapter of the ACA, local community service boards, and Facebook user groups to recruit licensed mental health counselors who have experience in a counseling relationship with adults with ID. The invitation presented and

explained the problem statement and outlined the purpose of the study. From the responses gathered, I selected a purposeful sample of eight counselors to participate individually in a single 90-minute semistructured interview. Qualitative research design dictates that sample size be at least five to 10 participants. Specifically, Lester (2009) suggested that phenomenological research participants often use fewer than 10 participants. Many published qualitative phenomenological designs range from between five to 10 participants (Atanasov, 2016; Crain & Koehn, 2012; Hill, 2010; Weiss et al., 2009).

Inclusion Criteria

My inclusion criteria were as such: licensed professional counselors in the state of Virginia. If it was found necessary to widen the geographical focus to obtain the appropriate number of participants, the mental health counselor participants were to be licensed by their respective state licensing agency. Also, a participant's counseling experiences with adults with ID were to consist of more than one session, and participants must have had 2 years of postlicensed experience at minimum. The counselor participants were to speak English and agree to audio recording of the interview. Lastly, the counselor participants were to live within an hour's drive or agree to use FaceTime or Skype video conferencing. I scheduled the participants for interviews as they were identified and consented to participate in the study.

Instrumentation

The instrumentation was a demographic sheet and a semistructured interview used for the data-collection process. In-person interviewing, whenever possible, was used to

gather the data. As needed, technology was implemented to aid in the ability to achieve the sample size (six to 10 mental health counselors). The demographic sheet was sent in advance to collect the data, and a 90-minute interview was used for each participant. The interviews were audio-recorded and transcribed.

Interview Process and Transcription

According to Seidman (2013), the purpose of the interview in phenomenology is to understand participant meaning derived from their experiences. Given the research question offered for this study, interviewing was the most natural direct methodology to achieve a contextual understanding of the research question about the lived experiences and the meaning of participant experiences about providing counseling services to adults with ID (Seidman, 2013). Once participants were identified, I sent a questionnaire to capture demographic information (years of experience, training, interventions used, type of professional setting; Appendix A). The information derived from the questionnaire helped to identify what counselors working with adults with ID have experienced and offered more information to guide the structured interviews with each participant and aid in maximizing the time allotted for the interview. I conduct a single 90-minute interview (Appendix B) with each participant that focused on the participant's history and experience counseling adults with ID, as well as the context and meaning-making of their experiences of counseling adults with ID. To maximize time and ensure that information was rich and thick, I used an open-ended questionnaire as a guide for the interview for each participant. I audio-recorded, transcribed, and member-checked the information for accuracy. I coded the information and used NVivo software to aid in the analysis of

themes (Maxwell, 2013). I recruited participants using an e-mail solicitation. I used the Virginia Chapter of the ACA, local community service boards, and Facebook user groups as vehicles to invite licensed mental health counselors who have counseling experience with adults with ID to participate in the study.

This recruitment process allowed the inclusion criteria to be met: licensed professional counselors in good standing with the Virginia Board of Counseling who self-identify as having actual counseling experience (more than one session) with adults with ID and have a minimum of 2 years' experience postlicensing. Inclusion criteria were limited to a minimum of 2 years of counseling experience to ensure that there were as many participants as possible for the study. This was based on research that suggested that there are a limited number of counseling professionals currently providing counseling services to adults with ID (Corbett, 2011; Prout & Browning, 2011). It was my hope that lowering the inclusion criteria to 2 years offered maximum latitude for counselor participation. The invitation explained the problem statement and outlined the purpose of the study. From the responses gathered, I determined a purposeful sample by the positive responses to the initial invitation e-mail. Out of the target goal of six to 10 participants, eight were ultimately selected for one 90-minute semistructured interview. Upon conclusion of the member-checking of each interview, I coded the interviews and used NVivo software to aid in the development of themes for analysis. Other sources of data were field notes and a personal journal. From the data, I bracketed information to reduce bias and identify emerging themes from the interviews (Maxwell, 2013; Seidman, 2013).

The interview took place in a quiet area, specifically of the individual participant's choosing, which allowed for a confidential distraction-free conversation. I first read the informed consent script and obtained the participant's signature on the consent form. Once the form was signed, then the recording and the interview began. The interviews lasted approximately 90 minutes. I had a semistructured set of questions that I asked each participant. My questions as outlined in Appendix B were open-ended and structured in obtaining information about the participant's experiences providing counseling with adults with ID. Moustakas (1994) recommended a prompt question format and I designed my interview questions to observe this format (Appendix B). Frequently it is necessary to ask follow-up and clarifying questions to ensure that the researcher is seeking out the experiences of the participant and not making assumptions about a particular experience. This is a necessary part of the process and is essential to use in order to minimize the possibility of bias on the part of the researcher.

The audio-recorded interviews were transcribed using Gee's transcription key (Gee, 1999). The transcripts included literal statements and also offered coding for paralinguistic emphasis as indicated. Once an interview was transcribed, it was checked against the audio to determine accuracy and corrected as needed.

Data Analysis Plan

Qualitative data analysis is dependent upon looking at large amounts of narrative information gathered from interviews using a purposeful sampling method (Creswell, 2014). Qualitative data analysis allows for the categorization of themes and concepts that emerge from interviews related to how people experience a particular phenomenon

(Creswell, 2014; Moustakas, 1994). I recorded, transcribed, and member-checked the data obtained from the interviews. I used Gee's transcription (Appendix D) to obtain areas of emphasis and para-linguistic nuances. Moustakas (1994) described a general process for data analysis. First, obtain a full description of the experiences of the phenomenon. Second, consider each the verbatim statements for significant utterances and take care to list nonrepetitive statements. Third, make descriptive and thematic connection and synthesize units of information into descriptions, using verbatim examples. Fourth, construct a description of your own experience and distill the information into a universal description of the experience (Moustakas, 1994).

Coding

Coding data in qualitative research is the process of reducing massive amounts of data into categories and themes (Creswell, 2014). Once the interviews were coded, I used NVivo software to sort the data. I interpreted the data produced from the interviews and the corresponding literature to help analyze the information to distill literature and offer insight into the lived experiences of mental health counselors providing counseling to adults with ID.

Issues of Trustworthiness

Trustworthiness is important when engaging in research. I took care to have a process of recruitment that was clear and fit ethical and evidenced-based guidelines to obtain a purposeful sampling procedure. I did not cross ethical boundaries, and I ensured that the data was maintained in a confidential manner and that proper informed consent was obtained from all participants. Data was procured through a process of formal

interview, audio recording, transcription, and member-checking for accuracy. The participant pool for this study is not a vulnerable population. This study has been reviewed by the Walden Institutional Review Board, via expedited application.

Where possible, I worked to eliminate the possibility of bias through keeping a field journal and by using bracketing to ensure that my thoughts were not overshadowing the interviewing process. Moustakas (1994) described the process of bracketing. Bracketing is described as the process of separating your personal thoughts, beliefs, and biases out of the narrative that the participant is sharing with you. This can occur during the interview, after the interview, and at any time while listening or considering the information derived in the interviews. The use of a field journal is how the researcher sets aside or brackets their thoughts in an effort to keep the personal reactions, thoughts, and beliefs separate from the narrative of the participant (Moustakas, 1994).

Ethical Procedures

As a process of ethical research standards, I have obtained permission to conduct the research via the Walden Institutional Review Board. I have used informed consent as an additional ethical protective measure, specifically, the informed consent used with each participant in the study. The informed consent allowed for full information about the voluntary nature of the study and the ability to withdraw, and also explained the risks and benefits of the study. The risks of the study were minimal and included the same minor discomforts encountered in daily life such as fatigue, stress, or minor agitation. If such risks were encountered, I would consult with my Chair and devise a plan to remedy the distress encountered. There were no risks in this study that presented a risk to the

participant's safety or well-being. I did not and will not disclose any names or other personally identifiable information for any participants in the study. I have secured all information gathered through the interviews in a locked cabinet and all electronic data secured on a password-protected computer to maintain confidentiality

Summary

This chapter outlined the methods for this qualitative phenomenological inquiry. I outlined the constructivist approach as a lens for this methodology. I identified the recruitment, sampling, and data analysis process required for the study. Chapter 4 outlines the results and a discussion of the study in detail with examples of the questionnaire and an outline of the semistructured interview.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to explore the lived experiences of mental health counselors providing care to adults with ID in a counseling relationship. In this chapter, I present demographic and data analysis of the interviews in which I explored the research question: What are the lived experiences of mental health counselors providing care to adults with ID? To obtain rich detail in the semistructured interviews, I asked the following questions:

1. What have you experienced as you have provided mental health services to adults with ID?
2. What types of situations or contexts are relevant when you worked with adults with ID in a counseling relationship?
3. What else do you believe would be relevant for me to understand more about your experiences with adults with ID in a counseling relationship?
4. Based on these experiences with the clients you have worked with, would you do anything different in your work with them?
5. What recommendations would you make to counselor educators about preparing counselors to address the needs of adults with ID?

As my research unfolded it became clear that to understand the lived experiences of mental health counselors in a more coherent manner, more questions were needed to fully explore the lived experiences. Subsequently, I added the following questions to offer further clarity:

6. Please reflect on your counselor education program and share your perception of your preparedness to address the needs of adults with ID.
7. Given our American Counseling Association (ACA) ethical mandate to maintain multicultural competencies, can you comment on your multicultural competencies to address the needs of adults with ID?

These questions provided additional insight, which I address in my findings section. Upon completion, I transcribed each interview using the Gee Transcription Key and utilized member-checking for accuracy. The Gee transcription method allows for added emphasis of pause, natural breaks in conversation, and other processes to capture the nature of verbal conversation into a transcribed document (Gee, 1999). Upon reviewing the transcriptions, I used the process as outlined by Miles, Huberman, and Saldaña (2014) and Creswell (2014), which included a global initial review of the transcripts. Hermeneutic phenomenology is a social constructivist process that seeks to derive meaning through understanding a person's lived experiences. In this manner, I tried to use the social constructivist phenomenological process to explore the lived experiences of mental health counselors actually providing care to adults with ID in a counseling relationship. During the review, I outlined key descriptive phrases in the participants' own words to fully offer depth and obtain the distilled essence of the participants' experiences. This helped ensure a full and thorough process for descriptive data analysis and interpretation appropriate to a hermeneutic study (Miles et al., 2014).

Methodology

In Chapter 3, I described my participant recruitment process, and I also received approval to conduct this research via Walden's Institutional Review Board (IRB number 09-12-17-0018728). Through my solicitation and recruitment efforts, eight participants meeting the specified inclusion criteria identified their willingness to engage in this research. The interviews were conducted in private settings and audio-recorded with the informed consent process implemented. In two of the interviews, FaceTime technology was used to conduct the interview due to the travel distance. Each interview lasted between 45 to 90 minutes. All data collected in the interviews were used for the data analysis.

Moustakas (1994) suggested that broad questions be used in qualitative phenomenological interviews to elicit thick, rich descriptive information from the research participants. I offered the participants an opportunity to share their unedited thoughts through responding to open-ended questions with minimal prompting. I did use clarifying questions to ensure that I could derive a clear description with detail about their lived experiences and to develop a meaningful descriptive context of their experiences while engaged in a counseling relationship with adults with ID (Miles et al., 2014). In concordance with a hermeneutic approach, I listened to each audio recording and read each transcript a minimum of three times. I used the process of developing key words and phrases, as described by Miles et al. (2014) and Creswell (2014), to develop codes and I reviewed the emerging themes through several iterations of theme review and development in my process. Once I developed the codes and themes, I used NVivo

(Version 11). This software aided in the organization of information in the interview transcripts. I also used my field journal, in which I recorded my personal reflections as I progressed through my eight interviews. This process allowed me to expand my interview questions to help capture additional information through the development of more questions in the semistructured interviews.

Participant Profiles

Eight participants gave of their time and shared personal experiences to contribute to this study. Of the interviewees, six were women and two were men, ranging in age from 29 to 70 years, and the experience in counseling as a licensed professional ranged from 2.5 to 15 years. Seven participants lived in Virginia and one participant lived in Texas. To maintain confidentiality, no names were used in the audio recordings or the transcripts. Each participant received an alphabet letter designation to maintain complete anonymity.

Demographics

Participant A is a 70-year-old man, practicing as a licensed professional for approximately 15 years with as many years of actual practice with adults with ID. He noted that, prior to his licensing, he worked for several years with adults with ID in various capacities (case manager, substance abuse counseling as a paraprofessional, and work as a special education teacher). His area of specialization is mental health (serious mental illness), substance abuse, and ID. His theoretical orientation is CBT and Rational emotive behavior therapy (REBT). He is in private practice.

Participant B is a 36-year-old woman, practicing as a licensed professional counselor for approximately 3 years, with 3 years of experience with adults with ID. However, she noted that she had more than 13 years of experiences with adults (mental health skill-building, direct support professional, and case management) with ID prior to being licensed.

Participant C is a 29-year-old woman, practicing as a licensed professional counselor for 4 years. She has served adults with ID as a professional counselor, but she noted that she had experience prior to her licensing as a positive behavioral support facilitator. Her theoretical orientation is CBT, and she uses mindfulness practices in her work. She is in private practice.

Participant D is a 43-year-old woman, practicing as a licensed professional counselor for 6 years. She has worked with adults with ID for 6 years, but also notes that prior to being licensed she worked as a case manager for dual-diagnosed adults (ID/MH). Her theoretical orientation is CBT, and she incorporates a variety of clinical interventions (motivational interviewing, SFBT, and mindfulness practices) in her work. She is in private practice.

Participant E is a 32-year-old woman, practicing for 2.5 years. She had prior experience in her postgraduate residency working with adults with ID as a mental health skill builder and working intensive in-home cases with a provider agency. She describes her theoretical orientation as eclectic. She uses CBT and somatic experiencing interventions in her work with individuals presenting with complex trauma. She is in private practice.

Participant F is a 42-year-old woman, practicing as a licensed professional counselor for 12 years. She has worked with adults with ID on a limited basis, working in community mental health and also in acute-care hospital care settings for the past 12 years. Her current practice setting is a combination of community mental health and private practice. She describes her theoretical orientation as CBT, humanistic, and existential.

Participant G is a 38-year-old man, practicing as a licensed professional counselor for 3 years. He has worked with adults with ID in an outpatient counseling relationship for the last 3 years. Prior to obtaining his license, he worked as a case manager for dually diagnosed individuals in a community mental-health setting. He currently works in a community mental-health setting. His area of specialization is working with individuals presenting with trauma, and he indicated that his theoretical orientation is trauma-focused CBT.

Participant H is a 40-year-old woman, practicing as a licensed professional counselor for the past 3.5 years. She has worked with adults with ID identified as sex offenders for 3.5 years. She is a certified sex-offender clinician with the state of Texas. Her theoretical orientation is reality therapy and choice therapy. She works in private practice.

Data Analysis

Hermeneutic phenomenology focuses on multiple participant perspectives and can provide a rich description to glean the essence of a lived experience (Moustakas, 1994). Phenomenological data analysis, as described by Creswell (2014), requires the researcher

engage in data management, immersion in the data collection through reading and listening, and the development of descriptions and classification leading to interpretation and presentation of information gleaned. In this spirit, my process for data analysis was to listen to the audio recordings and read each transcript a minimum of three times. I color-coded the descriptive words and used NVivo to help me organize the information and develop themes that emerged throughout the data. I have outlined the themes that emerged and related them back to the primary research question.

The following themes emerged through the data analysis: stigma, same life issues, adaptations, exposure, and counselor education. I address each thematic category and offer information about overlapping themes. It is important to note that these themes emerged as I organized the data from the interview transcripts, my field journal, and the coding entered into NVivo. I address each theme individually.

Stigma and Marginalization

Adults with ID are highly stigmatized or marginalized (Corbett, 2011; Irvine & Beail, 2016; Taylor & Knapp, 2013). All the participants interviewed offered perspectives that indicated they believed that adults with ID are a highly stigmatized/marginalized group in society, with this marginalization identified by both the individual as well as the majority of the counselors through their therapeutic interactions. For instance, Participant A conveyed that the clients with whom he has worked make statements like, “I feel like I do not count,” “People do not listen to me,” and “People only see my label.” Participant B relates that clients tell her that “No one listens to me, I feel like they are not listening to me, and this makes me mad and that is

why I will not do what they ask me to do." Participant E discussed an experience with one person she was counseling and stated that it became clear that her client wanted to make choices, and all his supports failed to hear what he wanted and then wondered why he was so angry. Six of the eight participants indicated their interactions with adults with ID left them with the belief that adults with ID feel they have "no voice" and, further, that the process of counseling may be one of the first times a person with ID is afforded an opportunity to express themselves and truly be heard. Participants D, E, and G indicated that their experiences with adults with ID illuminated the notion that this client population are rarely afforded the opportunity to choose for themselves and experience little autonomy in even the basic aspects of their lives.

All participants expressed the perspective that adults with ID who are dependent on multiple caregivers—or who live with their family—have little choice and do not orchestrate their own lives, partly due to their skill deficits, but also partly due to the support systems that surround them. For example, Participant A stated, "I often felt like they were treated as second-class folk, and that people only see the label and not the person." This perspective was developed through his previous exposure to adults with ID via special education and case management. Participant F detailed a perspective that adults with ID are "cast aside in our society," with Participant F basing this upon the observed lack of services and the invisibility of adults with ID in their communities. All participants identified this as an internal belief or experience of adults with ID, and a way in which adults with ID viewed themselves. Participants A, F, G, and H noted, in fact, that adults with ID have made direct statements acknowledging their personal awareness

of the stigma of their disability. Furthermore, with this belief came less of an ability to—and a frustration about how to—manage the day-to-day aspects of their lives.

Same Life Issues

There was a common theme that adults with ID present with the very same life issues as nondisabled people. Specific references in the data revealed the following key phrases from five of the eight interviewees: *they are just like us*, and *they want what we want*. Participant G perceived that adults with ID struggle with grief over their lack of ability to have a life like those without ID (i.e., marriage, children, and the ability to be seen as normal people). Participants E and G discussed exposure to traumatic events like sexual assault, or the constant loss of care providers, as factors that impacted the adults with ID that they supported. There was a shared perception that adults with ID are particularly vulnerable to experiencing life issues due to lack of supports and that they may have little ability to express how they feel about what is happening in their lives. Participants D and E discussed their work with adults with ID who were demonstrating depressive symptoms as it related to grief. In some cases, the person was not able to attend the funeral of a loved one and, as such, had no closure for the loss they experienced. Participant D discussed how she worked with a person who had lost their parent and had not attended the funeral—and was only told that their mother had gone to heaven—and so the person had not had an opportunity to explore personal meaning of that loss. Through counseling, the client was able to express how sad and alone they felt since the death of their parent, and the counselor indicated the client seemed to be relieved to know that what they felt was okay and a normal experience. Moreover, six

participants (A, B, C, D, E, and G) indicated, diagnostically, many adults with ID struggle with depression, anxiety, grief issues, isolation, and associated problems with having limitations in their ability to have choice and autonomy in their lives. This aligns with the literature presented in Chapter 2. Further, Participant C described some of the presenting problems related to the referrals she received:

> So I've never really seen anybody that's just coming because of an intellectual disability. So currently I see a young lady who has– who is diagnosed with Down syndrome and she's presenting with depression symptoms. I see another young lady right now who is diagnosed with autism and her presenting concern is anxiety. Many times, I see people with disabilities because of behavioral issues rather than a mental health diagnosis. So like they would get referred to therapy because, Johnny is setting things on fire [or] Johnny is not getting along with his roommate.

There was a global perspective among the interviewees that most adults with ID do not overtly ask for assistance to cope, but instead may express their difficulties with maladaptive behaviors (aggression and other self-limiting behaviors). Depending on the expressive and receptive communication skills, the adult with ID experiences limitations in the ability to verbally express distressful emotions and will need support to do so. There seemed to be agreement among the majority of the participants interviewed about the importance of understanding expressive and receptive communication skills to help tailor therapeutic adaptations to the individual's strengths. Concurrently, another shared participant experience was that many adults with ID do not self-refer for counseling

services and may not understand what to expect in counseling. For example, the participants shared the following observations and experiences: “They were just being brought to outpatient therapy and the person was unsure why they are here” (Participant B); “They may have been just brought by their group home or family member and no one told them why they were coming” (Participant D and E); “Adults with ID have a lack of awareness of how others perceive their behaviors” (Participant C); “Behavioral communication of frustration or other strong emotions is due to unexpressed or unheard needs in their environments” (Participant G). However, according to Participants C, G, and H, once educated about therapy, adults with ID are very open and genuine, and benefit from the counseling experience. In fact, six of eight participants indicated that adults with ID “want to get better… and desire symptom relief” and are genuine in their desires and work hard in the therapy process.

Adaptations

The data offered a great amount of insight into the essential considerations when working with adults with ID in a counseling relationship. Specifically, the following key phrases were identified after a global review of all the transcripts: “meet them where they are,” “take an individualized approach,” “slow the pace down,” “make concepts simpler,” “meet the person where they are and stay in the moment,” “it is important to use repetition in the counseling process,” “use of metaphors that person can related to,” “being more directive in the therapy process is helpful,” “eight to 12 sessions doesn’t work,” “education of the client and the caregiver,” “problem-focused,” “understand the person’s expressive and receptive communication skills,” “it is important to get their

psychological evaluation to use as baseline information about strengths and deficits," and "have a creative and flexible mindset." Also, the use of worksheets, music, props, visual aids, and physical activity to accommodate shorter attention spans were routinely noted.

Adaptations are an important part of working with adults with ID (Irvine & Beail, 2016; Morasky, 2007). The participants perceived adaptations as necessary and accomplishable when working with adults with ID in a counseling relationship. My interpretation of these adaptations as expressed by the participants is the conviction that mental health counselors must have a flexible mindset and a need to be creative to make the therapy effective and productive for adults with ID. Many participants expressed the need to compensate for client level of ability (e.g., verbal skills, vocabulary, shorter attention spans, lack of understanding about the purpose of counseling to the person presenting for support). Clearly, the premise of "meeting the client where they are" is a central skill taught in counselor-education programs and an important counselor skill. Participant F imparted the following:

> I had to get really creative. And I really had to take a person-centered approach as well. Because every client is different. What works for one person doesn't necessarily work for another person. I had to find out what was going to meet the need of every individual client. I used lots of work sheets, visual cues, diagrams, and verbal commands, and needed to be a bit more directive in my communication.

The participant perceptions about adaptations is aligned with the literature presented in Chapter 2 (Irvine & Beail, 2016; Morasky, 2007; Raffensperger, 2009; Taylor & Knapp, 2013).

Another insight that emerged from the perceptions of the interviewees was related to the referral sources that were connected to the person in counseling. Participant C shared her experience of feeling frustrated about the logistical issues and motivation for seeking care expressed by the referral sources. Specifically, if an adult with ID was referred to counseling and they lived in a group home, there were many factors about this living environment that seem to complicate the process of therapy. One factor, according to Participant C, was the logistics of getting the person to the session. There were frequently missed and rescheduled appointments due to problems associated with multiple caregivers. Issues like, "the van doesn't work," "another client had an appointment," and "the staff member called out and there was no one to bring the client to the therapy session" were cited as reasons presented for broken appointments. Another concern expressed by five of eight interviewees was that the person was sent to counseling to address a "problem" and, along with this, there was an expectation that the counselor needed to be problem-focused as well. For instance, Participant C expressed the following:

> So I think, in general, with individuals with disabilities there is a communication barrier there for people who they are typically around the majority of the day. So, for me, I really used our sessions– really a big chunk in the beginning was just rapport-building. And so I realized a lot of them just want to be heard. A lot of

> them just want to be understood. And they don't have many of those opportunities on a daily basis with the revolving direct-support staff that they work with, and the individuals that they live with who also have communication barriers. So I would get some resistance from caretakers because they wanted them to come to counseling to stop things where that was not my number-one priority in our sessions. And so, throughout the process, there was a lot of education to the caretakers or to the direct support staff. So I would remember when they would drop the individuals off and make statements like 'Don't forget to tell your counselor what you did yesterday' or 'Don't forget to tell your therapist this.' Whereas I didn't really care a lot about that. I really wanted to build rapport with them and really get down to why they're doing the things that the caretaker wanted them to stop.

Multiple participants shared frustrations about the complexity of managing the concerns expressed by the referent and not allowing that to outweigh the concerns expressed by the client. Additionally, interviewees expressed a need to manage expectations by the referral sources as a process of ongoing education in the purpose of counseling and the therapist's role. As previously mentioned, many interviewees discussed the need to educate the person as an adaptation of therapy, but also shared a greater frustration about managing expectations by group-home personnel and families who seemed to expect that counseling sessions would serve to immediately ameliorate the specific concern (i.e., problematic behavior) that had prompted the referral to counseling. Participant D indicated the following:

> And now that also includes bringing in someone else, and usually as a licensed professional counselor we don't use support… bringing in a support on someone into the counseling session is not typically what we do as we work individually, you know. But sometimes we have to just to get the background information. I find it difficult just to get that from the individual who's receiving counseling, so we have to bring in someone—either a support provider from their home, or a family member who can kind of give us that information. The only issue I have with that, though—when they're here providing support—getting them to understand that it's not *your* session, *this is theirs*. And so I run into an issue where while we're providing support… I even tend to see this with some of my individuals who I'm working with– that they tend to look at their support provider for answer. And that's not what I want. I want to kind of get into, 'Okay, how do we support this individual and what's going on with them?' And that can be kind of difficult, you know, when you have another person who's telling you what they think instead of the individual telling us, you know, what's going on/what they think, and how to process this.

At least seven of the eight participants expressed frustration about the complications presented by referral sources, but they also maintained the need to have ongoing contact with the referral source to ensure that they could obtain meaningful information about how the focus person is functioning within the environment, a need due to verbal limitations, poor memory and/or inability to offer sufficient detail about what was happening, by the adult with ID in the counseling session. Four of the eight

participants, through previous exposure to other aspects of training, applied behavioral analysis or Positive Behavioral Support facilitation, and used some data-collection processes, to help maintain information about the frequency of target behaviors—identified by referral sources—to offer more insight about what was happening between counseling sessions. These issues greatly impacted the course of therapy, making it much more intensive than traditional outpatient therapy. Additionally, nearly all participants felt that this variable also impacted the length of therapy, and it was seen as not being the traditional eight to 12 sessions to achieve successful outcomes.

Another concept that emerged through the interviews was the perception of resources. Many of the participants described significant variances in resources available when reflecting on the adults with ID they encountered. The majority of the participants interviewed had some community mental-health experience as the main vehicle that increased the likelihood of interacting with adults with ID. Participant B worked primarily in community mental-health-practice settings, and offered her perception about the lack of resources for adults with ID if they were not recipients of the long-term waiver services. The long-term waiver funding services provided wrap-around supports (housing, staff support with the home and community, and access to employment or day supports). If the adult with ID was not connected to a long-term funding stream, there were sparse community-based supports available. Participant B stated, “I was struck by what seemed to be an all-or-nothing support dynamic, depending on funding—or lack of it.” Three participants indicated that working with adults with ID who did not have access to this funding created lots of difficulty within the counseling arena because many

struggled with accessing basic needs (housing, employment, and healthcare), frequently propelling them into crisis.

The predominant therapeutic orientation lens and theory-based interventions were CBT (trauma-informed CBT), DBT, humanistic, and somatic experiencing. The data did not reveal specific challenges, or at least the participants did not express problems with adaptations for the interventions used. The predominant use of CBT theory and techniques supports the efficacy and strengths of CBT, DBT, and person-centered approaches when working with adults with ID as reviewed in Chapter 2 (Corbett, 2011; Irvine & Beail, 2016; Raffensperger, 2009).

Exposure to Adults with ID

When coding the data, a common theme emerged regarding the participants' exposure to adults with ID. The participants were exposed to adults with ID through professional experiences, and through familial or social experiences. Professional exposure was through special education, community mental-health settings, direct-support professional work in residential or day programs, and through ancillary services like applied behavioral analysis or positive behavioral facilitation services. Familial exposure was identified as being related (i.e., brother, sister, uncle, aunt, or parent), and social exposure defined as a neighbor or friendship connections. Seven of the eight participants had this type of exposure (professional or familial) typically prior to their licensing. Through clarifying questions, each participant expressed being affected their exposure to adults with ID and viewed this experience as a salient factor in their openness to working with adults with ID in a counseling relationship. Five of eight participants

agreed that lack of exposure to adults with ID is a major barrier for other mental health counselors' willingness to work with this population. The perspectives were mixed about why mental health counselors without exposure seemed to be limited in engaging with adults with ID. Participant G shared his perceptions of how other mental health counselors view adults with ID:

> Well it's sort of this, Oh, they have an intellectual disability… oh, I'm not sure that I can do therapy with them. And even though you might tell the counselor that you have to modify some things and use less-complicated language– but many times folks [counselors without exposure] who have not been with adults with intellectual disabilities believe they [adults with ID] cannot benefit from therapy. And I don't know… I mean I call it a fear, but I think, *they don't have the skills to do this*.

Other participant statements about why those counselors without exposure do not see adults with ID in counseling, are: "You do not know what you do not know" (Participant G); "People do not see adults with ID because of the separation of the systems of care" (Participant H); "Some counselors are fearful that they do not have the skills to work with adults with ID" (Participant H); "Adults with ID do not have the skills to participate in insight-driven therapy" (Participant B). There seemed to be a shared perception that there exists a lack of mental health counselors who are willing to work with adults with ID, and that the lack of exposure to adults with ID is a contributing factor as to why many counselors do not provide services to adults with ID.

Counselor Education

Counselor education was a key theme identified. As the interviews progressed, I needed to expand the semistructured interviews to inquire about the participants' experiences and reflections on their own counselor-education preparedness programs. This line of questioning revealed another question related to developing a better understanding of the perceptions and experiences of their personal multicultural competencies, and how they related their competencies to address the needs of adults with ID in counseling relationship.

Perceptions about counselor education programs. After a thorough review of all of the interviews, there was a unified agreement among participants about the lack of specific discussion or preparation about how to address the needs of adults with ID. Specific statements to this effect were: "I received no training about how to address the needs of adults with ID," "I do not believe we covered anything specific to adults with ID," "I think it was very general and covered theories, but it did not prepare me to effectively work with adults in counseling relationship," "I do not recall ever discussing the needs of adults with ID needing counseling in my program." Participant B reflected, "Everything I learned about working with adults with ID happened after I graduated from school... I was offered a course on applied behavioral principals and learned about 'behavior as communication'—and this really shaped me, and helped me develop a skillset in addressing issues presented by adults with ID." While none of the participants explicitly cited frustration regarding their lack of preparedness, I did sense that this frustration was present. However, I was also left with a sense that the participants

interviewed enjoyed a flexible mindset and embodied a commitment to meeting clients in the moment, along with the humanistic principles of unconditional positive regard. In some cases, it was clear that a participant's previous exposure correlated to a willingness to embrace the challenges associated with adults with ID. Participant A stated: "Once I got going with a client with ID, I rarely thought about the client's disability and focused on making the session meet the client's needs. I think this is due to my previous exposure to folks as a case manager and a special educator."

In terms of multicultural competency, six of the eight participants felt that there was a "gap" in competency since disability, of any type—cognitive or physical—was not a diversity topic really addressed in their programs. One participant, on the other hand, felt that there was not a gap in multicultural competencies because people with disabilities fit into all of the other major diversity categories, while the remaining participant indicated that she had never considered the aspect of disability as a diversity category. The majority of the participants indicated they had a deeper appreciation for this issue now that the question was posed. Some reflected on the social justice aspects of their personal impressions about the stigma and marginalization that they have observed and sensed from adults with ID.

All participants agreed that counselor educators can better prepare emerging counselor professionals to serve the needs of adults with ID through an enhanced syllabus, integrating concerns about ID and other developmental disability issues into counselor preparedness curriculums. It was particularly relevant that the concept of disability as a diversity category was not overtly discussed in their counselor-education

preparedness programs. Additionally, all participants indicated that internships and practicum experiences would greatly enhance exposure. Lack of exposure to adults with ID was listed as a perceived barrier to the development of increased counselor supports to adults with ID.

Counselor Rewards and Frustrations

It was clear after reviewing the data from the combined interviews that there was both a sense of immense reward on the part of the participants as well as frustration in their work with adults with ID. In terms of rewards, several participants revealed that they perceived adults with ID to be a very unique and genuine group of people who had very specific needs. Participants experienced a sense of pride in that they were able to facilitate, perhaps for the first time for many adults with ID, the ability to "be heard" and be truly listened to. Counseling literature suggests that the therapeutic relationship is a powerful factor in healing (Seligman, 2006). Other expressions of fulfillment were related to statements about being immersed in the work and actually forgetting the concept of ID when working with adults with ID. Participant A, for instance, shared the thought, "Sometimes when I got rolling in my work with the client, I forgot about the ID component."

This combined sense of positive experience with adults with ID was also coupled with some frustrations. Frustrations expressed were in experiencing concerns about their own ability to truly meet the needs of the adult with ID in the counseling relations. This notion aligns with the study presented by Viecili, MacMullin, Weiss & Lunsky (2010) that supports the premise that predictive factors of mental health providers being open to

working with adults with ID is related to exposure. Hemm et al. (2014) explored literature citing counselor frustrations about the lack of training, and identified a need for more consultative resources to other professionals who were more familiar with adults with ID. Examples of frustrations experienced by participants of the present study are, "I wonder if this [technique or adaptation] is helping the person," and "I wonder if they are getting it?" Also noted by participants was feeling conflicted about the need to use referral or support persons to help obtain information about functioning, and then needing to manage the multiple priorities as expressed by both client and the referral source. Participants A, B, C, and G shared the feeling that they could never really prepare for some of their clients because they did not really know in advance what the concerns would be. Often participants recognized that just "being in the moment" and feeling that the ability to offer acceptance and true interest in the internal thoughts and feelings of the focus person was a powerful intervention all by itself.

Results

The following section is devoted to offering a summary of the research question: what are the lived experiences of mental health counselors providing care to adults with ID in a counseling relationship? This research offered an understanding of the actual experiences of mental health counselors working with adults with ID. My first insight gained through my interactions with the participants is the perspective that adults with ID are a very vulnerable group in our society who are subjected to immense stigma and marginalization. The stigma is a palpable experience that is clearly recognized by all of the mental health counselors interviewed. There was a recognition that adults with ID are

also acutely aware of the stigma of their disability, and this is seen through the recognition that they are treated differently and have limited ability to experience full and enriched lives by virtue of their increased support needs. This stigma also leads to situations in which adults have little voice and experience minimal autonomy in basic aspect of their lives.

Another shared counselor experience is an awareness that adults with ID have similar life issues to which they must navigate. However, adults with ID experience more difficulty resulting from communication limitations and decreased autonomy due to multiple caregivers or living with family. The study participants have lived experiences where they recognize that the diagnostic assessment picture is not always clear, and there is always a co-occurring mental health diagnosis in every adult with ID that they have supported. The diagnostic picture is often murky and takes time to sort out. One participant indicated that she need to pull in as much information as possible to help establish a clear picture of functioning. Many participants indicated that gathering collateral information is even more salient in their work with adults with ID. This is needed to ameliorate the verbal skill deficits, concreteness, and poor memory presented by the adult with ID when presenting for counseling. Mental health counselors used a variety of theoretical lenses (CBT, DBT, somatic experiencing, humanistic, and trauma-informed) with which they conceptualized their work as counselors. In all the interviews, the lived experiences of the participants interviewed demonstrated that each of the theories cited could be adapted to meet the needs of adults with ID. Each participant shared in the commitment to be creative and find adaptive ways to work with adults with

ID. However, there was a common expressed theme that the more severe the level of ID, the more the participant's tended to employ true behavioral principles. A shared lived experience identified a concern that the participant's own counselor-education preparation did little to assist them to meet the needs of adults with ID in the community. Exposure prior to or in conjunction with their counselor-education training was a predictive factor in their openness to work with adults with ID. The lived experiences of mental health counselors suggest that they are truly an admirable group who have a sincere desire to address the needs of adult with ID, and at times questioned their own ability to meet these needs. However, this questioning did not yield a reluctance to serve, but instead inspired them to be creative and bridge the gap in services for adults with ID.

Nonconforming Data

Eight participants were recruited and selected based upon the inclusion criteria. Minor differences did emerge when exploring their individualized experiences. Specifically, Participant H did not have any prior exposure (professional or familial) to adults with ID prior to beginning her work as a licensed professional with the population. Additionally, Participant H's work centered around forensic evaluations of sex offenders, some of whom were identified as having an intellectual disability. No other participants had experience related to forensic clinical encounters. There was no significance in the nonconforming data collected and, due to the nature of inquiry into lived experiences of participants in hermeneutic phenomenology, all data points serve to add depth and breadth to the research process.

Evidence of Trustworthiness

To address the procedures of qualitative research, specifically hermeneutic phenomenology, I followed the processes as outlined by Miles et al. (2014), Moustakas (1994), and Creswell (2014) to engage in interviewing, data collection, coding, and data analysis. I listened to and read the interview transcripts to reach saturation of information (Miles et al., 2014). From there, I coded descriptive information and then moved to a second review of the descriptive information to develop themes (Miles et al., 2014). This process offered a true distillation of information available in the process. As an additional measure, I kept my own notes in my field journal to allow for "bracketing of information" as a means to keep my personal perspectives and insights separate from the actual data collected. Once I transcribed the interviews, I utilized member-checking as a process in my design to increase trustworthiness. All participants confirmed the accuracy of the data collection and the authenticity of the interview data collected.

Summary

The purpose of this qualitative hermeneutical phenomenology was to explore the lived experiences of mental health counselors providing care to adults with ID in a counseling relationship. The research process revealed that mental health counselors who work with adults with ID are sensitive to the unique needs of the population. Collectively, the mental health counselor's interviewed were acutely aware of the stigma and marginalization that impacts the day-to-day lives of adults with ID. The lived experiences of mental health counselors working with adults with ID reveal that adults with ID are vulnerable, and typically are referred to counseling to address "problem behaviors."

Mental health counselors working with adults with ID have successfully utilized mainstream counseling theories like CBT, DBT, trauma-informed CBT, somatic experiencing, and humanistic lenses in their work. They do note that adaptations are needed to compensate for verbal fund of knowledge, poor memory, and concrete thinking. With the appropriate adaptations, the lived experiences suggest that adults with ID are eager and willing participants in the therapeutic process. Mental health counselors believe that exposure to adults with ID will greatly enhance counselors being open to providing services. The mental health counselors in this study shared a belief that their counselor-education programs did not properly prepare them to meet the needs of adults with ID. Additionally, many expressed that there was a distinct gap in multicultural competencies, as it related to disability being a diversity topic. Lastly, mental health counselors endorse changes in counselor educator curriculum to address these gaps in counselor preparedness and counselor multicultural competency.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In this chapter, I review the interpretations of the findings of this study, the limitations of the study, the implications for social change, and recommendations for future research. My research was a phenomenological hermeneutic inquiry into the lived experiences of mental health counselors working with adults with ID. In this study, I interviewed eight licensed mental health counselors who had experience in a counseling relationship with an adult with ID. The bulk of this research occurred with mental health counselors residing in Virginia and one participant who lived and worked in Texas. I sought to understand shared lived experiences of respective counselors engaged in a counseling relationship with adults with ID. I used a semistructured interview (Appendix B) to collect data, which I recorded and transcribed. The interviews were the sole data-collection source for the findings. The research question for this study was as follows: What are the lived experiences of mental health counselors providing care to adults with ID?

Interpretation of the Findings

As the interviews unfolded, several common themes emerged in relation to how mental health counselors perceive their work with adults with ID. Specifically, the following themes presented themselves: stigma and marginalization, same life issues, adaptations, exposure, and counselor education. The interpretations of the data are based upon the phenomenological process and reaching back into the literature to determine connections from the peer-reviewed body of literature presented in Chapter 2.

Stigma and Same Life Issues

The recognition of stigma was a focal point revealed from the data captured from all participants in the study. Each participant had a keen sense of the impact of stigma and marginalization on adults with ID. The participants were aware of the way in which society views individuals with ID, and they were also aware of the connection between this same stigma as it relates to how adults with ID view themselves. The perceptions of the counselors supported the belief that adults with ID are frequently subjected to marginalization as a result of their disability. Specific counselor statements like, "I often felt like they were treated as second-class folk and that people only see the label and not the person," and recurrent phrases from study participants like "cast aside in our society" support the perceptions that adults with ID are not a particularly visible client population as compared to other diversity groups. All the counselors interviewed recognized how support needs, limitations in autonomy, and limitations in their ability to self-advocate impact the quality of life for adults with ID. There was a general understanding that many adults with ID have behavioral problems due to these limitations but are frustrated in their limited ability to fully communicate how their life circumstances affect them.

Another connection to the theme of marginalization is the perception from the participants that adults with ID rarely have a "voice" and "do not feel heard." There was an acknowledgement that the clients who the participants worked with were not self-referred and that the counseling experience for many of these clients was recognized by the participants as perhaps one of the first times that someone ever really inquired about how adults with ID felt about their lives and offered an unconditional ear. Bertelli et al.

(2015) and Bouras and Holt (2010) discussed the neglected mental health needs of adults with ID, and associated it with DO and the fact that adults with ID are a very vulnerable and marginalized group within culture. Irvine and Beail (2016) offered information about the specific vulnerabilities of adults with ID and cited the separation of the systems of care for ID services and mainstream mental health services as a rationale for the minimal referrals for mental health counseling. Also, adults with ID rarely were self-referred for mental health care (Deb et al., 2015; Donley et al., 2012; Feldman et al., 2004; Oliver et al., 2005; Raffensperger, 2009). Instead, adults with ID are frequently referred to outpatient psychiatry and acute inpatient care settings due to concerns about aggression, self-injurious behavior, property destruction, and so forth, and treated with atypical antipsychotic medications to address what is considered problem behavior (Corbett, 2011; Feldman et al., 2004; Oliver et al., 2005; Raffensperger, 2009).

Corbett (2011) discussed the impact of marginalization and social exclusion for adults with ID, both in their respective communities and within the greater mental health arena. Corbett identified the concept that adults with ID not being viable parts of the community translated into the beliefs and lived experiences of various professionals involved and, once reified, has resulted in the distancing of the mental health community from addressing the needs of adults with ID in the clinical realm. The literature aligned with the study participants' perceptions and experiences.

The literature on inclusion represents an example of advocacy leading to the paradigm shift from institutionalized services to community-based services. Inclusion was bolstered by the ADA of 1990 legislation, and particularly the Olmstead Act of 1999

ruling, which helped propel the tide of deinstitutionalization (Larson et al., 2012). Even with large reductions in institutional-based care populations, however, community-based mental health services still are woefully inadequate to meet the unique needs of adults with ID in their communities. Bouras and Holt (2010) discussed how separate care systems in the United Kingdom and other European countries resulted in minimal supports for mental health for adults with ID once adults with ID were transitioned into the community. Larson et al. (2012) and Lemay (2009) echoed similar concerns for the trend of deinstitutionalization in the United States. Once deinstitutionalization occurred, the community-based mental health services were ill-equipped to address the unique and complex needs of adults with ID. Matson and Scior (2004) discussed differences in stigma and clinician bias in determining a mental health diagnosis.

Given the concerns about deinstitutionalization as cited in previous literature, adults with ID identified as experiencing problems with transition and, due to cognitive limitations, are susceptible to increased stress connected with living in the community. In this study, the participants identified similar life stressors that impacted the adults with ID that they supported in counseling. Participants concurred that adults with ID share similar life issues in particular—trauma, family separation, unemployment, low socioeconomic status, social isolation, grief and loss, lack of autonomy, and dependence on others for help—and agreed that adults with ID were inherently more vulnerable in their ability to cope and respond to various life stressors. Given these vulnerabilities, adults with ID are more susceptible to mental health disorders. In fact, the prevalence of mental health disorders for adults with ID is estimated to be twice the prevalence of co-occurring

mental health disorders when compared to the general population (APA, 2000, 2013; Corbett, 2011; Irvine & Beail, 2016; Taylor & Knapp, 2013). All the participants were acutely aware of the vulnerabilities of their clients, and the participants' perceptions of the presenting problems were similar to those cited in the literature.

Exposure

Exposure was illuminated as an emergent theme and was a significant factor in counselors' openness to working with adults with ID. All but one counselor had a prior connection to adults with ID based upon either family connection to a person with ID or professional exposure through working in the field of ID (direct support professional, special education, community mental health counseling, and/or positive behavioral supports). All the participants expressed that their exposure to adults with ID was a predictive factor in their willingness to engage with adults with ID in a counseling relationship. Some participants believed that increased awareness on their part of the unique needs of adults with ID came from their recognition for the need for advocacy for the population and the development of sensitivity and appreciation that adults with ID are vulnerable and in need of supports. Reiss, Levitan and Szyszko (1982) coined the term *diagnostic overshadowing* and defined it as clinician bias that prevents an adult with ID from receiving a diagnosis of a coexisting mental health disorder that a person with average intelligence with the same symptoms would receive. The lack of exposure can also be a form of clinician bias and, as such, can have an impact on counselor willingness to offer mental health counseling to adults with ID.

Counselor perceptions are shaped through exposure and experience. This is important to note because the theoretical lens for this study is social constructivism. Schwandt (2000) offered that a social constructivist lens helps people make meaning of their respective experiences. According to Schwandt, knowledge is not a passive experience but instead an active experience where the mind develops meanings and concepts. In other words, people make meaning or develop beliefs about their experience. In terms of counselor exposure to adults with ID, the lack of exposure can lead to a perception or belief that adults with ID do not need or benefit from counseling experience. Taylor and Knapp (2013) discussed the lack of research and training for mental health practitioners with adults with ID and co-occurring mental health disorders. The lack of training and exposure leads to clinician bias that mental health counseling is not appropriate for adults with ID (Corbett, 2011). Currently, the majority of mental health interventions for adults with ID occur in the form of outpatient psychiatry prescribing atypical antipsychotics to address problem behavioral crises as identified by caregivers (Hatton & Taylor, 2013; Irvine & Beail, 2016; Jahoda, 2016; Jopp & Keys, 2001). The mental health counselors interviewed echoed perceptions that the adults with ID they encountered were being seen by psychiatrists and were heavily medicated. Additionally, the mental health counselors believed that behavioral crises seemed to be a major factor leading referrals to psychiatrists, resulting in acute inpatient hospitalization.

Counselor Adaptations

Counseling interventions can be effective in remediating mental health distress for adults with ID (Clute, 2010; Dodd et al., 2013; Nicoll et al., 2013, Oathamshaw &

Haddock, 2006). The counselors interviewed in this study identified specific adaptations for the counseling interventions offered to the adults with ID. Moreover, the participants agreed that there were several adaptations necessary to ensure that the counseling was effective. In fact, participants identified that adults with ID rarely self-referred and did not understand the purpose of counseling. This finding is in concordance with Dagnan et al. (2013), who identified that adults with ID were not being educated about the option of therapy and thus, if they were referred to therapy, had little understanding of the expectations. However, Dagnan et al. concluded that once adults with ID understand how counseling can assist them with concerns that they have, they adapt and are willing participants. Education about therapy was determined to be a main adaptation from the participant interviews. Other adaptations, as identified by the participants, were pacing (slower and individualized), being more directive, using creativity, and introducing visual aids (e.g., charts, pictures, worksheets, etc.). These adaptations were described in rich detail by all participants interviewed. The interviewees' perceptions of the adaptations were that they were necessary and added to the productive experiences of adults with ID. Charlton and Dykstra (2011) and Morasky (2007) offered specific recommendations for counseling adaptations to address problems related to poor memory, limited verbal skills, and short attention spans. Their recommendations were in using repetition, a direct therapist approach, slowing the pace of counseling, role play, use of multiple modalities of presenting information (visual, auditory, kinesthetic), and using language that is understood by the individual. Throughout the interviews with the participants, each

offered their endorsement of specific adaptations to address short attention spans, poor memory, and limited verbal skills.

From a social constructivist theoretical lens, the experiences of the interviewees offered rich and thick detail about how their adaptations were effective in their work with adults with ID. In many cases, the perceptions of the interviewees were shaped through their previous exposure to adults with ID, either professional, social, or familial. I concluded that exposure to adults with ID enhanced their willingness to engage with adults with ID, because they previously viewed adults with ID as a vulnerable clinical population with very specific needs. The majority of the participants appeared to be generally committed to be more flexible in their approach and also in expanding their creativity, despite feeling an undertone of frustration about their effectiveness with the client. I gleaned that the sense of frustration expressed by the participants centered around their concerns about their own competency and the ability to determine if interventions were effective. Many of the counselors interviewed suggested that they needed to measure their expectations differently when working with adults with ID. Making comparison to treatment progress of non-cognitively disabled clients was unrealistic and served to increase counselor frustration. In this study, counselor perceptions indicated that the foundational principles of Rogerian person-centered counseling techniques of unconditional positive regard, developing a strong therapeutic alliance, and of meeting the client where they are, worked to help alleviate concerns about competency. Also, Viecili et al. (2010) cited counselor frustration about their perceived competency when considering their ability to effectively work with adults with

ID, related to their lack of preparedness. Drucker (2011) discussed the process of supervising interns when working with adults with ID. Drucker asserted that when interns are supported to adjust for cognitive differences, there was no difference than when supervising interns working with other client populations. The counselor adaptations described by the participants aligned with the literature as presented in Chapter 2.

Counselor Perceptions of Preparedness

The counselors interviewed shared a common perception that they felt ill-prepared to work with adults with ID. All interviewees recalled minimal or no discussion in their counselor-education preparation programs reviewing the needs of adults with ID in a counseling relationship. Through clarifying questions, the conversation turned toward the concept of multicultural competency as it relates to working with the concept of disability. Clearly, the counselors interviewed were able to identify how the stigma of disability, specifically ID, affected the clients with whom they worked. The majority of the counselors interviewed also discussed being sensitive to their own recognition of how marginalized adults with ID were in their own communities. Specific references to this issue had to do with counselor perceptions of the available resources to support the adults with ID in the communities. Participants were acutely aware of the differences in available funding as being a variable affecting outcomes in therapy for adults with ID. One counselor compared and contrasted adults with ID who had long-term waiver services with those who did not. For those clients connected with long-term waiver services, there seemed to be varying degrees of choice and autonomy. When adults with ID were not connected with long-term waiver services, however, they struggled with

obtaining basic needs and had minimal support systems. The literature regarding deinstitutionalization cited the separation of treatment systems, developmental disability, and the community mental health system as barriers for adults with ID in the community (Larson et al., 2012; Lemay, 2009). Given the legacy of institutionalization, community mental health systems were ill-equipped to address the unique needs of adults with ID transitioning from institutions to the community (Larson, et al., 2012; Lemay, 2009). Other concepts like DO were identified as a variable that limited the ability for adults with ID to access the full range of mental health services (Charlot & Beasley, 2013; Jopp & Keys. 2001; Matson & Scior, 2004). Instead, increased utilization rates for outpatient and acute inpatient hospitalization supported the primary care vehicles for adults with ID needing emergent treatment for behavioral challenges like property destruction, aggression, and self-injurious behaviors (Bouras & Holt, 2010; Cain et al., 2010; Frances et al., 2014). Researchers identified DO as a barrier that contributes to the limitations of mental health services (Bhaumik et al., 2011; Charlot & Beasley, 2013; Corbett, 2011; Hurley, 2006; Irvine & Beail, 2016; Raffensperger, 2009; Taylor & Knapp, 2010). However, the study participants identified limitations as a function of exposure. Either way, all the study participants identified stigma and marginalization being a factor at both ends of the resource continuum.

All the counselors interviewed shared concerns about perceived deficits in their preparatory programs. The recommendations suggested by the study participants for counselor educators are an increased emphasis on exploring the concept of disability, integrating information into counseling-preparation programs about the needs of adults

with ID when engaged in counseling, and exposure to adults with ID in counseling practicums and internships. Counselors interviewed believed that exposure to and education about the unique needs of adults with ID may enhance or increase access to community-based counseling for adults with ID.

Costello et al. (2010) reported limited studies that examine the effectiveness of training programs for those providing mental health services to adults with ID. Viecili et al. (2010) endorsed the predictive factors leading psychology students to embrace working with adult with ID as a combination of exposure and integrated formal coursework. Hemm et al. (2014) conducted a mixed-methods review of literature of health care professionals working with adults with ID in the United Kingdom. The themes identified through this literature review identified that clinicians expressed frustration about limitations in their perceived training and readiness to serve adults with ID, and identified more training needs in assessment, diagnosis, interventions, and management of health—both physical and emotional—for adults with ID. These assertions as identified in the literature were endorsed by the study participants. As identified in the literature, the study findings identified a consistent counselor perception of frustration and perceptions of concerns about lack of training.

Limitations of the Study

There are limitations to this study. The first limitation is the nature of the phenomenological study. This can be limited through the process of researcher bias, assumptions, and subjectivity, all of which can impact researcher interpretation of the data and analysis (Creswell, 2014; Denzin & Lincoln, 2005). Within the tradition of

qualitative research, the guard against this specified limitation is the process of bracketing. In this vein, I took great care to bracket away my beliefs and assumptions throughout the interview process to limit the potential for bias. Interviewing was the primary vehicle for data collection and analysis—which could lend for the possibility of participant reaction to the role of the interviewer. Specifically, aspects of the reactivity of the participant could manifest in a participant feeling a need to please the researcher by offering information perceived as satisfying the interviewer's expectations, or, alternatively, a participant could present as guarded during the interviewing process. Given this potential, the role of researcher was to openly offer an informed consent process that clearly identified the purpose of the research and the theoretical lens—social constructivism—with which was sought to determine participant meanings, and not researcher meanings.

Another limitation is the sample size. The sample size interviewed was eight licensed mental health counselors. Creswell (2014) offered that a small sample size and the interpretive process of phenomenology makes generalization of the findings to broader population difficult. The design of this study is replicable, but the results may not be transferable to other groups due to the inability to control for confounding variables. Seven of the eight participants interviewed live in Virginia. Given this is a specific locality, the results from the participants are potentially skewed by local cultural and regional variables. In order to mitigate some of the limitations, I used a systematic data collection as well as a field journal to bracket away my thoughts from those of my research participants. Additionally, the interviews were audio-recorded and then

transcribed—with member-checking for accuracy. All of these methods were used to control for researcher bias.

Implications for Social Change

The social justice implications for this research are important. The goal of the research was to understand the lived experiences of mental health counselors providing care to adults with ID. The review of the literature offered substantial information regarding the significant vulnerabilities of adults with ID. Specifically, adults with ID are at increased risk for developing a mental health disability (APA, 2013; Corbett, 2011; Irvine & Beail, 2016). Other social and psychological vulnerabilities include limitations in communication, poor social support networks, lack of autonomy, and poverty, as well as susceptibility to abuse, neglect and exploitation (Corbett, 2011; Raffensperger, 2009). Adults with ID are a heavily medicated population, and have high utilization rates of acute hospitalization, but have limited access to mental health counseling as a systemic approach to obtaining wellness (Bhaumik et al., 2011). It is an important aspect of care to ensure that services are appropriate and assist with prevention of mental health disability and increase quality of life for all citizens of the community. Given the increase toward deinstitutionalization, more and more adults with ID will be transitioning to the community. In order to properly meet the needs of adults with ID in the community, mental health counselors must have the opportunity to receive training and exposure in order to facilitate those mental health needs as an inclusive part of the full range of mental health services in the broad community. Corbett (2011) discussed the need to end the social distancing that occurs when adults with ID are generally excluded from

counseling services. The social distancing that occurs in relation to how adults with ID are perceived within their communities is an issue ripe for increased research as it applies in how to address multicultural competencies. Seven of the eight participants in this study readily identified that disability needs more emphasis vis-à-vis developing increased sensitivity regarding ability versus disability in our culture. Lastly, the lack of counseling options for adults with ID presents a problem, because it does not comply with the multicultural ethical mandate supported by the ACA and CACREP standards. These standards outline the edict supporting the necessity to offer competent counseling services that appeal to diverse groups (ACA, 2014; CACREP, 2009).

At the local and state level, the study focused on identifying participants in the state of Virginia. Virginia, as indicated previously, is in the midst of systemic change due to the DOJ settlement and the closure of institutions. With the influx of adults with ID transitioning to the community, it is necessary to increase access to mental health care to assist with transitional issues of a complete lifestyle change. Virginia will need to rise to the task of ensuring that hundreds of vulnerable adults, along with those adults with ID currently in the community, can fully access mental health counseling options to assist with their emotional wellness needs. Ensuring appropriate and timely access to mental health counseling as a part of the repertoire of mental health services will help to augment and potentially insulate adults experiencing transition issues and also address life issues that impact quality of life. Increasing access to the full complement of mental health services will have larger societal implications because adults with ID are currently high-service utilizers for expensive acute inpatient hospitalization, and poorly treated

adults with ID who require intensive supports will impact placements in residential providers and potentially jeopardize public health in that aggression is a factor in need of support.

Recommendations for Future Research

The literature presented in this study clearly indicates that adults with ID are receiving inadequate care to address their mental health needs. This study presents the lived experiences of mental health counselors providing care to adults with ID. The findings reveal that mental health counselors perceive that adults with ID are a very vulnerable clinical group in our society and that stigma & marginalization are barriers to receiving the full range of mental health services available. The participants in this study acknowledged that adults with ID, once properly prepared to receive counseling, do quite well and actually make efforts to get better. Counselor perceptions about their work with adults with ID present that such adults do well with the tenets of counseling, with specific adaptations. Additionally, the therapeutic alliance is a significant factor in helping them function and progress within the relationship. A recommendation for future research is to investigate which counselor adaptations are most successful in working with adults with ID. Additionally, the theoretical orientations identified by the participants in the study ranged from CBT, DBT, humanistic, and person-centered, suggesting that these interventions are helpful with adaptations.

Another area for increased research would be counselor-education preparation programs and investigating how to increase exposure and specific curricula information that will enhance counselor preparation and self-efficacy when working with adults with

ID in a counseling relationship. It will be impactful to determine how increasing access to the adults with ID within the community mental health systems can help increase exposure to adults with ID in counseling settings. Likewise, it will be important to study the distinct systems of care for the developmentally disabled and the community mental health systems and working to understand how they can better align to increase access for adults with ID to the full range of mental health resources.

Lastly, the data offered in this study presented an interesting area to increase understanding about the multicultural competency area of ability and disability and how we as counselors can better recognize it and understand client impact. The participants in this study unanimously felt that the concepts of ability versus disability were not vigorously discussed in their counselor-education programs, as were other diversity categories. Given this lack of robust emphasis, it may be a signal to counselor educators about the need to be more intentional about identifying this diversity concept and increasing counselor awareness about how stigma and marginalization impact people presenting with a lifelong disability.

Conclusion

Adults with ID are a vulnerable group within our society. As the wave of deinstitutionalization sweeps forward, adults with ID are increasingly integrated into the community. Adults with ID experience twice the rate of co-occurring mental health disorders when compared to the general population (APA, 2013). However, adults with ID are typically treated for problem behaviors associated with property destruction and

aggression, as well as self-injurious behaviors. Adults with ID have historically received limited access to mental health resources like counseling.

The objective of this study was to understand and capture the lived experiences of mental health counselors working with adults with ID in counseling relationship. Additionally, the goal was to examine and interpret the meanings ascribed by mental health counselors working with adults with ID in a counseling relationship to determine the meaning applied to their work. The research question investigated was, what are the lived experiences of mental health counselors providing care to adults with ID? I used a hermeneutic phenomenological methodology to interpret and distill the meanings of the lived experiences of mental health counselors providing care to adults with ID. I used purposive and snowball sampling methods to recruit and interview eight licensed mental health counselors with experience in counseling relationship. I used open-ended semistructured interview questions (Appendix B) as the instrument to obtain data about the counselors' lived experiences.

Through this process, I identified the following themes: stigma and marginalization, same life issues, adaptations, exposure, and counselor education. A primary perception of mental health counselors working with adults with ID is the impact of stigma and marginalization on quality of life. Counselors and adults with ID receiving care are acutely aware of stigma and experience limited opportunities to be and feel heard. The perceptions of mental health counselors working with adults with ID is that therapeutic alliance can be strong, and that theoretical interventions of CBT, DBT, person-centered, and humanistic approaches with adaptations can and do benefit adults

with ID in a counseling relationship. Mental health counselors believe that exposure is a great predictive factor in helping future counselors become more open to addressing the unique needs of adults with ID in the community. Lastly, the perceptions of mental health counselors are that counselor-education preparedness programs are not addressing the needs of adults with ID—or perhaps missing a vital aspect of multicultural competency—by not having a more robust consideration of the unique concerns of people presenting with disability in our society. It is time to open up the counseling venue to be fully inclusive of adults with ID into counseling. Counseling is preventative and seeks to help develop strengths and heal people who are struggling with life issues. Adults with ID are a particularly vulnerable client demographic who are not receiving the full benefit of counseling to assist with developing a wholeness, ultimately limiting the quality of life for millions of our citizens.

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Appendix A: Demographic Sheet

Age _____

Gender _____

Years Licensed _____

Years of practice with adults with ID _____

Years of practice _____

Area of Specialization _____

Populations Served _____

Theoretical Orientation/Specific Theoretical Training _____

Therapeutic Interventions used _____

Type of practice setting _____

Private Practice _____

Community Mental Health organization _____

Training Facility _____

Hospital setting _____

What are your referral sources? _____

Appendix B: Semistructured Interview Questions

1) What have you experienced as you have provided mental health services to adults with ID?
2) What types of situations or contexts are relevant when you worked with adults with ID in a counseling relationship?
3) What else do you believe would be relevant for me to understand more about your experiences with adults with ID in a counseling relationship?
4) Based on this experience with the clients that you have worked with, would you do anything different in your work with them?
5) What recommendations would you make to counselor educators about preparing counselors to address the needs of adults with ID?

Appendix C: E-mail Solicitation

Hello, my name is Cynthia L. Minto, LPC. I am a Counselor Education and Supervision doctoral student at Walden University. I am conducting a qualitative phenomenological inquiry about the experiences of mental health counselors who have provided mental health counseling services specifically to adults with intellectual disability. I am inviting you to participate in this research due to your affiliation and professional identity as a Licensed Professional Counselor in the State of Virginia.

Participation in this research includes completing a brief demographic questionnaire and scheduling a 90-minute appointment to allow me to offer a semistructured interview about your experiences with adults with intellectual disability in a counseling relationship. Upon conclusion of the interview, I will verify your information by offering you a transcribed transcript of the interview to allow you to check for accuracy. Given that you are spending your valuable time, I would like to offer a $25 certificate for your time and consideration of the study. If you agree to participate in this study, your total time commitment shall not exceed 2 hours (inclusive of the time to complete the demographic questionnaire and the 90-minute semistructured interview). If you have any questions or would like to participate in the research, please respond to this email with "I consent." If you have any specific questions about this study, I can be reached at (XXX) XXX-XXXX or *XXXXX@XXXXX.XXX*.

Appendix D: Gee Transcription Key

CAPS	Vocal emphasis
?	Rising intonation or pitch glide
.	Falling intonation or pitch glide
!	Rising emphasis
–	Utterance broken off
=	Successive utterance with no gap
[ ]	Interviewer utterance
{ }	Author explanations
{p}	Short pause
{P}	Longer pause
/	Separates units of ideas/phrases
Hard return	Indicates a line or one topic
Blank line	Separates stanzas or paragraphs

(Gee, 1999)